Funeral Service in America — What Consumers Think and Want

According to a 2012 consumer survey conducted by the National Funeral Directors Association, about 75 percent of respondents felt that a funeral was either “extremely important” or “important” to the grieving and healing process. This article discusses today’s funeral service industry, citing several recent studies that shed light on consumer perceptions and expectations.

Managing Dyspnea

Dyspnea is one of the most debilitating and frightening symptoms that hospice patients experience. Likewise, there are few symptoms that evoke more distress on the part of caregivers. NCHPP’s Physician Section leader, Dan Maison, MD, FAAHPM, reviews its common causes, specific treatments, and the role of the entire team in alleviating symptoms.

Counseling the Patient for Better Quality of Life

By Teri Collet, ACSW, LCSW, ACHP-SW

The social workers and chaplains among us know firsthand that no two cases are ever the same. That said, there are common needs and concerns which hospice patients and families face — from trauma related to the diagnosis and prognosis, fears of being a burden, and ever-decreasing energy to more complex issues related to identity issues and role reversal.

How can we help them cope and, hopefully, find closure? This article reviews some of the tried-and-true techniques that can help both new counselors to the field and seasoned professionals, along with guidance to assist in documenting these interventions in a clinically significant manner.

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Helping Them to ‘Open Up’

Before we can assess the issues that pertain to a specific patient — and provide the best-possible support — we must help the patient and family express what they need and want. The following four interventions can be very useful as part of this process:

**Generalizing/Normalizing the Experience**

This involves helping patients understand that their feelings are common and expected, and can help decrease any defensiveness. For example, saying “Do you have any regrets?” is generally less effective than saying “So many people I talk with find themselves looking back at different times in their life and identifying things they wish they had said or done. Is this something you’ve experienced?” By posing the question in this way, the patient will be more likely to share any feelings of guilt or regrets.

In addition, we know that the end-of-life process is unfamiliar, so many patients may feel isolated and alone. Through generalizing and normalizing statements, we can decrease the isolation the patient may be feeling.

**Using Thinking vs Feeling Words**

Some people have difficulty identifying emotions and others have preconceived ideas (or perhaps pre-judge) professionals who attempt to explore feelings. In these cases, using thinking words can facilitate the expression of emotion. For example, instead of saying “Do you have any fears?” it may be more fruitful to ask “Do you have anything that concerns or worries you?”

For those patients who have trouble falling asleep at night, ask them: “When you are all alone with your thoughts in the still of the night what runs through your mind?” This can be a very effective way to elicit their fears in a nonthreatening manner.

**Mirroring — But With Words**

When many of us were pursuing our counseling degrees, we heard a lot about the value of mirroring clients. Unfortunately, so often what was taught was physical mirroring where we replicated our client’s body language, such as leaning forward or backward as the client did. While doing so, we often looked like mimes! But mirroring with words is a valuable way of showing our patients that we understand them. It also helps them to explore their feelings on a much deeper level.

For example, when encouraging patients to talk about their beliefs — and what comes next after leaving this world — using the same words they had used affirms their beliefs and our acceptance and support of these beliefs. This technique is also helpful when patients describe their regrets, though depending on the colorful vocabulary the patient uses, it may require the counselor to modify his or her word choices.

**Education on the Value of Sharing**

For some patients, helping them to understand the value of sharing information, memories or any concerns is all that’s needed to facilitate communication.

For other patients who are withholding information in order to protect others, it is important to discuss the isolation that will
The first six months of the New Year have been both busy and challenging — what I would say is the “new normal” for all of us. So I think the month of July is a good time to pause and take stock of everything around us that is going well.

Here at the National Center, we are in the midst of NHPCO’s annual renewal campaign and I’m proud to report that, as we go to press, renewals are coming in strong and steady.

While this is certainly a testament to the value of membership, I think it also reflects the importance that providers place on maintaining a cohesive hospice community — which is absolutely critical right now. So on behalf of the entire NHPCO board and staff, thank you! Let me also thank and welcome our new members whom I hope to have the chance to meet at one or more of our upcoming events.

The first of these events is approaching fast. The Hospice Action Network is hosting its second annual Advocacy Intensive on July 29–30 at the historic Washington Court Hotel in DC. This free event will provide policy and advocacy training to hospice staff at all levels as well as time on the Hill to meet face-to-face with members of Congress. Like last year’s Intensive, the goal is to convene a small but diverse group who can share the stories of hospice care that will resonate beyond the “usual rhetoric.” This year, with the recent reintroduction of the HELP Hospice Act, the Intensive’s timing could not be better.

In late September, NHPCO will also hold its annual Clinical Team Conference in Kansas City. This conference is held to provide training and support to the staff and clinicians from the myriad disciplines that make hospice care so unique. Due to sold-out attendance at last year’s CTC, we are also offering two-day Pediatric Palliative Care training as a preconference offering. We are finding that, in light of the Concurrent Care for Children provision in the Affordable Care Act, providers are eager to prepare their staffs for increasing pediatric referrals.

While registration for the Advocacy Intensive ends on July 8, there is certainly time to consider sending staff to CTC. I hope to see many of you at one or both events.

J. Donald Schumacher, PsyD
President/CEO
often result from internalizing their feelings, as well as the emotional distance it creates in their relationships at a time when closeness is so deeply desired.

When it comes to protecting children, it is quite effective to discuss the development of the child, and the benefit to the child if he or she is able to have closure. It is also helpful to educate the patient about the negative impact of withholding information from the child (e.g., how children sense the emotional dynamics in the home; how not having open communication about the situation can cause more distress; how they will use their imagination or erroneous information to “fill in the gaps” if not given age-appropriate information in a supportive manner). Helping patients to see the positives and negatives will increase their ability to share.

Making the Assessment

Understanding the issues that are significant to the patient at this time in his or her life is a critical first step in effective intervention. And, while we often think of life review as a valuable intervention, it can also be a great assessment tool.

The very process of life review can assist the social worker or chaplain in exploring areas of anxiety or concern, or unresolved issues. As a helpful analogy, think of life review as a fishing trip. The fisherman uses his or her knowledge and experience to determine the best location, depth and temperature of water and time of day where fish are most likely to be found, just as the social worker or chaplain, in understanding end-of-life issues, knows which areas to explore with the patient and when it is wise to move on. This process of exploration — a fishing trip so to speak — continues until a specific topic resonates with the patient. The social worker or chaplain can then use his or her skills to help bring about resolution.

We can also use probing questions to help patients identify deep-seated issues or concerns. For example, it’s very common to hear patients say “I’m scared” or “This is so hard.” To get at what he or she means, ask “What are some of the scariest parts?” or “What is the hardest part?” As we probe, we encourage the patient to look deeper into the nature of the fear or issue which can then lead to his or her own self-discovery. We can then use that to drive our future interventions.

Don’t Overlook the Common Interventions

Listening

We can never underestimate the value of allowing people to tell their stories. As helping professionals, we oftentimes feel compelled to do or say something to help fix a situation...
It is also important to validate a patient’s experience...

when, in fact, the patient can move toward healing just by telling his or her story.

When people have an accident, the early renditions of the story are very lengthy and very detailed, as if they’re reliving it. They clearly describe the experience, step-by-step, as they process the emotion behind it. However, after time and repetition, the story becomes more abbreviated, with less and less detail. This is due, in significant part, to the resolution of the emotional issues related to the accident.

We know that receiving information from a healthcare professional about a serious diagnosis and terminal prognosis is a traumatic event. Many thoughts and feelings need to be processed in order for the patient to experience resolution of the emotional impact of this information. Helping professionals in general, and the counseling disciplines specifically, need to encourage patients to tell their stories in order to work through the associated emotions. As such, we should never underestimate the value of active listening.

**Validation**
Simply put, this means acknowledgment of the patient’s feelings, situation and perceptions as real and significant. Validation is an effective way that any member of the interdisciplinary team can support and demonstrate the compassion of hospice care. For those in the counseling disciplines, it will also help establish and reinforce the therapeutic relationship. As much as we talk about validation of feelings and thoughts, it is also important to validate a patient’s experience (e.g., that the diagnosis or prognosis is unjust; his or her role in the family or social circle; the impact of his or her life on others).

**Providing Alternatives**
Sometimes patients feel stuck in their current situation; they are unable to see any options or they feel out of control. Illuminating alternative paths and options is very beneficial. For example, when patients are feeling like a burden to their caregivers or struggling with the changes in how they express their sexuality, it can help to have them focus on their legacy by exploring memorializing activities and how they want to be remembered. This approach can also help the patients who are finding it difficult to accept increasing dependence on others or those who are grieving the loss of a role. Realizing that one has options, no matter how limited or

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distasteful, can help the patient feel “less stuck.” While difficult, we can help by assisting them in choosing not necessarily the “best option,” but perhaps the “least bad” option.

**Education on the Dying Process**
We often focus this education on caregivers; however, a patient’s anxiety can also be reduced through education about what to expect. Some patients may want as many details as possible about each step — from their current level of functioning to their last breath. Others, on the other hand, want information one step at a time. One patient that I counseled wanted to know what to expect, but “not too far in advance.” After clarification, I understood that she wanted to know that her current experience was normal and what the likely next step would be. She said that she didn’t want to “look too far down the road,” though she didn’t want to be surprised either.

**Education on Allocation of Energy**
Most patients underestimate the fatigue that comes from being terminally ill, so it’s important to encourage them to do only those things that are most important to them and use their energy wisely. In fact, helping patients to understand and accept their limitations and prepare them to make conscious choices about how to spend their time is a vital role of the entire team. If we do not, they may waste their precious energy and miss out on some of those special moments.

**Addressing Legal Affairs**
Some people are very concerned about getting their affairs in order while they’re able to do so, while others are far less comfortable with such tasks. For those who want to be involved, education about the legal documents that will be required to facilitate access to finances or the transfer of assets is very beneficial. Far too often those who are ill are unaware of the prolonged incapacitation that precedes death and, as a result, many are unprepared as their condition worsens. We need to educate them about what to expect and provide the resources to help them with the process.

**Worry About a Love One**
So often patients will say they are worried about close friends and family they will leave behind. Reminding them of the caregiver’s natural support system, as well as the bereavement support services that will be available to their family, can provide comfort and peace of mind.

**Education on Role Modeling**
Patients will tell you that they feel like a burden to their loved ones and are interfering with the lives of their adult children or grandchildren. We certainly can’t minimize the challenges and disruptions that confront everyone involved when a person is terminally ill, but we can reframe their perception by reminding them that they are role models too. Parents, grandparents, and other family members are all role models, whether they are aware of it or not. Children learn to nurture by being nurtured and they learn how to function within their family because of how they see
others live. It is equally important to reinforce that needing help at the end of life is a natural part of this final developmental stage and that this is role modeling too. It demonstrates how to receive care as well as provide care — both of which are valuable life skills.

**Documenting Interventions**

Because our interactions with patients are typically informal and conversational, it can sometimes be challenging to document our interventions in a clinically significant manner, especially when under tight time constraints. We have to shift gears mentally — and quickly.

Below you’ll find a list of intervention words and phrases. I encourage you to place them on your clipboard, laptop, or within handy reach when documenting your interventions. They can save you time when searching for the best words to describe a patient visit.

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Our role as counselors is to help patients have closure in those relationships or situations that are unresolved, and help families find peace and start the grieving process. Through increased awareness of the common issues faced at the end of life, and employing high-quality interventions, we can facilitate true quality of life.

*Teri Collet has been the director of social services at Community Hospice in Modesto, California since 1999. She is also a national speaker and the author of numerous educational materials for patients and their families, including the booklet “Making the Most of Every Moment: A Patient’s Guide to Living with Hospice,” published by Limbertwig Press.*
According to a 2012 consumer survey conducted by the National Funeral Directors Association (NFDA), about 75 percent of respondents felt that a funeral was either extremely important or important to the grieving and healing process. This feedback alone points to the value of improving understanding and communication between hospice professionals and funeral directors — the very goal of a new collaboration between NHPCO and NFDA.

Through this collaboration — and the sharing of information and resources — both organizations hope to open up communication channels and foster mutual respect within their respective fields.

In this article, Jessica Koth discusses today's funeral service industry, citing several recent studies that shed light on consumer perceptions and expectations.
Since the beginning of time, humankind has always had to answer the question of what to do with the dead. Regardless of how that question has been answered, one thing is certain: the death of a loved one — be it a relative or a friend — is a life-changing experience. As hospice professionals, you witness firsthand how a death — even when it is expected — can cause an emotional upheaval from which a family must recover.

Funerals and memorial services offer a place and time to do just that. They offer the bereaved an opportunity to acknowledge the reality of death and the pain of the loss. At funerals and memorial services, families remember and honor the significant place their loved one held in their life, and caring friends offer support and comfort. Funerals and memorial services provide a place to begin the healing process.

Perhaps Dr. Thomas G. Long, Bandy Professor of Preaching at the Candler School of Theology at Emory University in Atlanta, said it best:

“Rituals of death rest on the basic need, recognized by all societies, to remove the bodies of the dead from among the living…. But no healthy society has ever treated this as a perfunctory task, a matter of mere disposal…. When we lift the heavy weight of the coffin and carry the dead over the tile floor of the crematory or across the muddy cemetery to the open grave, we bear public witness that this was a person with a whole and embodied life, one that, even in its ambiguity and brokenness, mattered and had substance. To carry the dead all the way to the place of farewell also acknowledges the reality that they are leaving us now, that they eventually will depart even from our frail communal memory as they travel on to whatever lies beyond.”

To put it even more simply, and in the words of poet and funeral director Thomas Lynch, “A good funeral gets the dead where they need to go and the living where they need to be.”

**Funeral Services Today**

According to the National Directory of Morticians Redbook, there are currently 19,624 funeral homes in the U.S. — a decrease from 21,710 a mere decade ago. Approximately 14 percent of funeral homes in the U.S. are owned by publicly traded corporations while the remaining 86 percent are privately owned by families or individuals.
The majority of these privately owned funeral homes are also quite small. For example, among NFDA-member funeral homes, 60 percent serve fewer than 150 families each year and nearly 65 percent only have one location.

The most recent economic census conducted by the U.S. Census Bureau shows that a total of 102,978 people work in funeral homes and funeral service (this includes both licensed and unlicensed employees, but excludes individuals working in cemeteries and crematories).

**Consumer Perceptions**

In 2012, NFDA conducted a survey to measure consumers’ awareness and perceptions of funerals and funeral services. A key result that stands out is that consumers think that taking time to commemorate the life of someone who died is important.

Three-quarters of survey respondents indicated that a funeral was either “extremely important” or “important” to the grieving and healing process. Only seven percent felt that it was “not at all important.” These results are consistent with other NFDA consumer surveys dating back to 2004.
These positive feelings about the importance of funerals aren’t just consistent with NFDA surveys. An April 2010 consumer survey conducted by Harris Interactive on behalf of the Funeral and Memorial Information Council (FAMIC) — “Study of American Attitudes Toward Ritualization and Memorialization” — showed that 92 percent of respondents “strongly” or “somewhat” agreed that a funeral service they attended had meaning and value, and reflected the life of their loved one. Nearly 90 percent “strongly” or “somewhat” agreed that the service they attended helped them to remember their loved one and say goodbye.

**Consumer Preferences**

So, if consumers feel funerals are important, what kind of service do they want? The answer, it turns out, is a service that is personal and meaningful — and focused on them.

A new study commissioned by the Funeral Service Foundation was released in 2012 and yielded deep insights into consumers’ perceptions about, among other things, the end-of-life ceremonies they want for themselves.

The study was conducted by Olson Zaltman Associates and used the firm’s pioneering Zaltman Metaphor Elicitation Technique (ZMET), which relies on psychological principles, rather than statistical ones.

The ZMET study showed that consumers want their funeral to be a transformative experience during which they come alive and the survivors offer comfort to one another and help each other heal. Or, as some ZMET study participants put it:

“[Death] is closing the book. We all have books, we all have chapters. We have history and experiences. It’s a summation of events.”

“I want people to have some food, to be able to talk and laugh… I don’t want it to be solemn. I want them to make it an event they would enjoy. Celebrating your life, the things you did, what you accomplished.”

“Life doesn’t stop when I die. Maybe someone can take a little bit of my enthusiasm or happiness or words of wisdom with them.”

A funeral can be transformative… healing… and comforting.
More Options Than Ever

Today, individuals and their families have more options than ever when planning a funeral or memorial service — from the simple to the very elaborate. Funeral directors stand ready to help families understand all of their options — no matter what their financial circumstances — so they can make informed decisions that will enable them to celebrate, honor and remember their loved one in the most meaningful way.

According to the FAMIC study, an overwhelming majority of consumers not only trust the funeral directors who have served them to provide the kind of funeral, memorial service or life celebration that they want, but they find value in the services they provide. The survey results showed:

- **95 percent of survey respondents strongly or somewhat agreed** that the funeral director took special care to make the ceremony and arrangements reflect the wishes of the family;

- **89 percent strongly or somewhat agreed** that people in funeral service are professional and competent.

- **89 percent strongly or somewhat agreed** that funeral directors have the expertise to recommend the right products and services.

- **93 percent strongly or somewhat agreed** that funeral directors are important in making funeral arrangements.

*Honoring the Deceased: Bottom Left — The memorabilia of a World War II Veteran punctuates the service held in his memory. Top Left — Funeral Director Paula Staab Polk reads “The Next Place” to the children attending their grandfather’s funeral, where they were also invited to place “STARS” in his casket as a final tribute to “Someone To Always Remember.” (Photos courtesy of Staab Polk Memorial Home, Chatham, IL.)*
Getting to Know the Services in Your Community

Just as you are your community’s experts on caring for individuals who have life-limiting illnesses, funeral directors are the local experts when it comes to planning personal and meaningful funeral and memorial services. Depending on your community, the families you serve may have several options. However, just like every hospice is different, every funeral home is also different. While there may be some similarities, the facilities, staff capabilities, pricing, services and amenities, and even goods (e.g., caskets, urns and other memorial items) can vary from one funeral home to the next.

Here are a few suggestions to help you get to know the funeral directors who serve your community and help them to get to know you:

• Take time to meet with funeral directors at your area funeral homes. Funeral directors are generally willing to take you on a tour of their facilities and help you understand the kind of services they can offer to families.

• Reciprocate by inviting the funeral home staff to your hospice for a tour and to learn more.

• Discuss ways you might partner on community outreach programs, such as a holiday memorial service or an end-of-life preparedness seminar.

• Explore ways that your hospice and local funeral homes can partner to offer bereavement support to those you mutually serve.

As the baby boomer population continues to age, we know the need and demand for quality end-of-life care will only increase. There is a tremendous opportunity for funeral service and hospice to work together to provide a continuum of compassionate care — to be of service to families and make what is surely a difficult and emotional time a little easier to bear.

NFDA is pleased to be working with NHPCO and the National Hospice Foundation to help our respective members learn more about one another and provide tools and resources to help create partnerships that benefit the individuals and families who will one day need our respective services.

Jessica Koth is the public relations manager for the National Funeral Directors Association.

To Learn More

The National Funeral Directors Association (NFDA) is the world’s leading and largest funeral service association, serving 19,700 individual members who represent more than 10,000 funeral homes in the United States and 39 countries around the world.

If you have questions about funeral service, what you can do to partner with NFDA or its members, or how to share the ways in which you are partnering with funeral homes in your community, contact the NFDA at nfda@nfda.org.
ehospice is a globally run news and information resource committed to offering the latest news, commentary and analysis from the world of hospice, palliative and end-of-life care. ehospice is a collaborative venture, with different editions developed for many nations across the globe.

ehospiceUSA is a free resource powered by NHPCO that has been created for a specific target audience—hospice referral sources. Any professional that may be caring for or supporting patients and families who may be appropriate for hospice will find useful information on ehospiceUSA.

NHPCO hopes that providers will share ehospiceUSA as a resource that will be helpful to the referral sources they work with in their communities across the country. Find this new resource at:

[www.ehospice.com/usa](http://www.ehospice.com/usa)
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Managing Dyspnea

By Daniel Maison, MD, FAAHPM

Anyone who has ever experienced the inability to get enough air to breathe can share with you how utterly and thoroughly terrifying dyspnea can be.

I for one had a near-drowning experience as a college student while body surfing in Mexico. While I was probably under water for less than a couple of minutes and the memory itself is now decades old, it felt like hours and I can still recall the experience as if it happened yesterday.

Now imagine experiencing that sensation every hour of every day or living with the fear that it could come back at any time, without warning.

Dyspnea is far and away one of the most debilitating and frightening symptoms our patients experience. Likewise, there are few symptoms that evoke more distress for caregivers than to be present when a loved one cannot get enough air. The presence of dyspnea demands an immediate, coordinated response involving the entire hospice team.

Anticipating when dyspnea might happen and having a plan in place for when it does are as important as knowing what to do. Since it is also one of the most challenging and complex symptoms we are called upon to alleviate, the treatment of dyspnea reveals the true value of team-based care and the value of having an interdisciplinary team when caring for patients.

This article will explore common causes of dyspnea, along with specific treatments and the role of the entire team in alleviating symptoms.

Dyspnea Defined

Dyspnea is the uncomfortable feeling of not getting enough air to breathe. In milder cases, it is described as “not having enough air” or “not being able to catch one’s breath” while in more intense cases it can feel like the person is suffocating. Breathing is something we do unconsciously, without having to think about it. So, when people notice that they “have to breathe,” chances are they may be experiencing some semblance of dyspnea.

*The National Council of Hospice and Palliative Professionals (NCHPP) is comprised of 15 discipline-specific Sections that represent the staff and volunteers who work for NHPCO provider-members. To learn more about this NCHPP Section, visit the NHPCO website.
Depending on the reason a patient is enrolled in hospice, dyspnea can be expected more or less commonly. For some diseases, such as chronic obstructive pulmonary disease (COPD), dyspnea may be the primary symptom a patient experiences as it occurs in the vast majority of COPD cases. For other illnesses, dyspnea may be less common. For example, depending on the type of cancer a patient has and the organ systems involved, dyspnea may play a larger or lesser role in a patient’s total symptom burden.

**More Than Just Physical Symptoms**

There are clearly physical and non-physical (e.g. psychological) components to the sensation of pain. Likewise, when people suffer chronically from pain, there is a psychological toll. This is also the case with dyspnea — and one of the reasons why it is key that we engage the expertise of our entire team in its treatment.

Additionally, dyspnea itself may manifest as other symptoms. For example, patients may experience anxiety or panic as their main subjective complaint and not necessarily have complete insight into the fact that dyspnea may be the reason they are feeling anxious in the first place. Conversely, someone suffering from anxiety or a panic attack might only report they “cannot breathe” and have little to no insight into the strong psychological component resulting in their experienced symptom. Likewise, anxiety and dyspnea may co-exist and present simultaneously. Who wouldn’t feel at least a little anxious if they could not get enough air to breathe?

An analogy I often use with patients is a situation that occurs with lower-back pain. When people injure their backs, they often experience both pain and muscle spasms. The muscle spasm increases the pain they experience and, simultaneously, the pain they experience can exacerbate the muscle spasm. It can become a vicious cycle and we need to treat both the pain and muscle spasms to provide them with relief.

Similarly, helping patients understand the connection between their overwhelming anxiety and the dyspnea they are experiencing can be essential if we ever hope to provide them with effective symptom control. If we only address the anxiety and not the underlying dyspnea that might be the cause, it is unlikely that we will be able to provide adequate relief of either.
Fix the Fixable

Depending on a patient’s underlying illnesses, there may be many things we can do to help reduce the frequency and/or severity of dyspnea.

When assessing a newly admitted patient with dyspnea, one of the most important things to consider is whether the underlying illness is being treated to the fullest extent possible. For example, are patients with congestive heart failure receiving optimal therapy? Are those with chronic obstructive pulmonary disease receiving all that they should in terms of medical management?

Additionally, many patients will experience dyspnea due to a condition that can be alleviated with a relatively simple procedure. For example, those with a pleural effusion can receive almost instant relief from a thoracentesis. For those with recurrent pleural effusions, the implantation of a pleural catheter will allow a patient and caregiver to remove fluid several times a week right at home. The bottom line is this: A thorough assessment will allow you to zero in on possible reversible causes of dyspnea and allow you to provide maximal palliation.

Doing the “Impossible”

Like many of you, our hospice organization has served many patients with a significant symptom burden who, because of our care, were able to achieve a level of comfort they had not experienced before. A patient I met early in my hospice career helped to demonstrate this to me in a way that I have never forgotten.

During my first year as a hospice physician, we were asked to admit a 78-year old gentleman with very advanced heart disease who had been in the hospital for two weeks and was no longer able to get out of bed. We were told he had days to weeks to live.

When we met him, we reviewed his history and medications. We got to know him well as hospice teams do. We found out that he had struggled with alcoholism in the past, that he had lost his job, and that his relationships with his family had been very strained for years. In fact, he hadn’t spoken to them in more than four years. He was spending all day, every day, in bed, and was becoming extremely dyspneic even when being helped out of bed. Most of the time, he had some level of symptoms
(mainly dyspnea) while at rest. He had been to the emergency department several times in the past two years, but had never followed up with an outpatient physician as he had been asked to do. We also discovered that he never filled prescriptions for his cardiac medications after leaving the emergency department.

Within about a week of being under our care, we noticed something. He seemed to need less and less medicine to help with what he called his “attacks” (i.e., episodes when he was unable to catch his breath and accompanied by an overwhelming sense of panic and fear). These attacks would respond to low doses of morphine (more on this later). When we first admitted him, they were happening four to six times per day. By the end of the first week, they only occurred once or twice a day. Within two weeks, they went down to once a day and, shortly thereafter, they became a rare occurrence.

Something else also started to happen. He had required large amounts of oxygen when he was first admitted. With each passing week, we were able to lower the amount of oxygen he needed to the point that, within eight weeks of his admission, he was comfortable without any supplemental oxygen. At the same time, he was able to do more and more. He went from spending almost all day, every day, in bed at the time of admission to being able to get around with a cane — all within the space of about six to eight weeks.

With his permission and the encouragement of the social worker and chaplain on our team, the patient reached out and reconnected with his family, repairing relationships that had been broken. He continued to improve and thrive. In fact, he did so well that we discharged him after six months. He lived another two years at home, independently, with excellent quality of life.

Imagine if we had not been called in to help care for him? He would have likely died in the hospital (versus two years later at home), miserable (versus well palliated), and never having had the chance to reconcile with his family (versus reconnecting with children he had not seen in years). Here was a patient we were told had days or weeks to live. We not only helped him live much better, the work of the hospice team allowed him to live much longer than his medical team thought possible.

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The most amazing thing to me isn’t that we were able to help this one person. Rather, what has amazed me is that he was the first of many patients for whom the hospice team did things others thought impossible, and did so on a routine basis.

**Treatments**

In addition to maximizing disease-specific medical treatments as I note above, let’s turn our attention to two of the main classes of medications we use for the palliation of dyspnea — anti-anxiety medications and the opiates.

**Anti-anxiety Medications**

Benzodiazepenes are the most common medications used to treat acute bouts of anxiety. Two oft-used members of this drug class include lorazepam (e.g. Ativan) and alprazolam (e.g. Xanax). This class deserves special attention as it is often the first medication used by non-hospice professionals to treat the anxiety caused by dyspnea and the type we often encounter when patients are referred to hospice. In this population, however, these medications are at best variably helpful.

**Opiates**

As research has borne out, the opiates (such as morphine) are the medication of choice for the symptomatic relief of dyspnea. Furthermore, when used for dyspnea, they often help alleviate the associated anxiety. At doses usually lower than those needed to alleviate pain, the opiates alleviate the sensation of dyspnea without affecting breathing rates. So, if not specifically an anti-anxiety medication, how do the opiates help treat anxiety?

Think about why the patient is anxious in the first place. If we remove the source of the anxiety itself (i.e. the dyspnea), the anxiety will also be treated. So, for patients who feel anxiety because they can’t catch their breath, if we take away their breathlessness, their anxiety will be alleviated too.

Additionally, don’t be surprised if your non-hospice colleagues express skepticism or even outright resistance to using opiate medications. There is a widely held belief that these medications are inappropriate or dangerous in this population due to concern that they will depress or even stop a patient’s breathing. As with any powerful medication used in a medically
frail patient, opiates must be used correctly and carefully. When used appropriately, they are safe and effective. And when used as we do in hospice, these medications alleviate dyspnea while posing little to no risk to our patients.

**Role of IDT in Treatment**

Hospice professionals have long recognized that a disease and its symptoms impact more than just the patient’s physical well-being. When someone is chronically unable to get enough air to breathe, how can it not affect their psyche, their sense of self? When someone can’t breathe, how can it not affect those around them?

The optimal treatment of dyspnea is a wonderful demonstration of the need for true interdisciplinary care. It calls for:

- Addressing the psychosocial needs of someone who has to reframe his or her role within the family;
- Helping patients and families explore their own spirituality as they face this distressing symptom;
- Supporting a patient and family with personal care as a disease progresses.

These are all things that our teams do every day, so it’s easy to start to consider these interventions as routine and ordinary. However, the work of the interdisciplinary team is anything but ordinary. Never forget that the work we all do is pretty amazing. And never forget the incredible things we can accomplish as a team.

**In Closing**

Dyspnea represents one of the most challenging symptoms our patients and their loved ones will ever face. Frightening and debilitating, its treatment requires expert, targeted, team-based work. And, as we often find in hospice, we are able to accomplish things as a team that none of us would ever be able to do individually. Thorough assessment and a team-based approach are key to its optimal treatment. Make sure you are engaging the entire interdisciplinary team in the care of those who suffer from dyspnea. Our patients and their loved ones deserve nothing less.

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Daniel Maison is the medical director of the Palliative Care Program at Spectrum Health, based in Grand Rapids, Michigan, as well as the Physician Section leader for NHPCO’s National Council of Hospice and Palliative Professionals. He is board certified in both internal medicine and hospice and palliative care, and is a Fellow of the American Academy of Hospice and Palliative Medicine. Dr. Maison also presents frequently at NHPCO’s national conferences.

References and Suggested Readings:


Help Your Patients Have Meaningful and Memorable Experiences with Family and Friends

Lighthouse of Hope Fund

The Lighthouse of Hope Fund is available to hospice patients

- Who are cared for by one of NHPCO’s hospice provider members
- Who have no other option for financial support for their specific request
- Whose application is submitted by a member of the hospice’s interdisciplinary team

With a $500 registration fee, hospices will receive up to $1,500 in total funding after patient requests are reviewed and approved. Funds may be used for one or more patient requests.

Special trips, outings or adventures with family can be a special experience for hospice patients and families.

Learn More:
www.NationalHospiceFoundation.org/LighthouseOfHopeFund
New Tip Sheets on Understanding and Managing Pain
Share With Patients, Families and Referral Sources

In May of 2012, NHPCO’s Caring Connections unveiled the LIVE Without Pain consumer campaign in partnership with Purdue Pharma, LP. The goal is to empower patients and family caregivers to advocate for expert pain relief in all care settings through education and how-to resources.

As part of this initiative, four new tip sheets have been developed:

- Physical Pain at End of Life
- Understanding Pain for Improved Quality of Life
- Caring for Someone in Pain
- Pain at the End of Life – Common Questions

You are welcome to make as many copies of these tip sheets as you wish to share with patients and families as well as your referral sources. Or you can purchase multiple copies through NHPCO’s Custom-Print Marketplace — with the option of adding your organization logo and a brief personalized message.

- To download a copy of each tip sheet, use the links above or visit LIVE Without Pain > Resources on the Caring Connections website.

- To order personalized copies, visit Custom-print Marketplace. (If you are a first-time user, you must register first. You will receive an immediate email confirmation with your access information.)

To learn more about the LIVE Without Pain initiative, visit www.caringinfo.org/pain.

LIVE Without Pain at September’s CTC
With funding support from Purdue Pharma, LP, a special preconference session about managing pain will be held in conjunction with the 2013 Clinical Team Conference. Look for more details to follow, or bookmark the Conference landing page for future reference.
Supporting Fathers and Other Males

Do men encounter different challenges or react and behave differently when confronted with a loved one’s serious illness? Especially if that loved one is a child? These questions are explored in the latest issue of NHPCO’s pediatric newsletter, edited and produced by members of the Children’s Project on Palliative/Hospice Services (ChiPPS).

“Our primary goal in this issue is to honor and promote the perspectives of these men,” note the editors. “And, at the same time, we also want to contribute to a better understanding of what it is like to walk in their shoes and how the assistance offered to them can be improved when a child is facing a life-threatening illness, is dying, or has already died.”

Download a copy of the issue — and feel free to share it with colleagues.

Be sure to also visit the Pediatrics section of the NHPCO website for past issues of the newsletter and other pediatric resources.
Karen Ann Quinlan Hospice Breaks Ground on Regional Residence

This past spring, the Karen Ann Quinlan Hospice broke ground on a $5 million, 10-bed regional residence that will provide short-term, acute, and respite care within its service area of northwest New Jersey and northeast Pennsylvania.

The Karen Ann Quinlan Hospice opened in 1980 and was named after the Quinlan’s daughter, Karen Ann, who in 1975, at the age of 21, inexplicably lapsed into a coma and a persistent vegetative state. At that time, her parents became the spokespeople for the right to die with dignity and the case became the catalyst for the global conversation about the importance of advance care planning.

Pat Gibbons Recognized as Triad Nurse of Distinction

Pat Gibbons, RN, BSN, the director of Beacon Place at Hospice and Palliative Care of Greensboro, was selected as the 2013 Triad Nurse of Distinction by the North Carolina Nurses Association.

The award recognizes a registered nurse who makes a positive impact on patients and the community. Gibbons, who has been in the field for 44 years, has led the 14-bed inpatient facility, Beacon Place, since it opened in 1996. She is also the former Nurse Section leader of NHPCO’s National Council of Hospice and Palliative Professionals, a position she held for eight years.

Florida Hospice & Palliative Care Association Announces Awards of Excellence Winners

In conjunction with its 28th Annual Forum, Florida Hospice & Palliative Care Association announced the winners of this year’s Awards of Excellence in Hospice and Palliative Care:

Excellence in Interdisciplinary Care: Elizabeth Caldwell, LifePath Hospice

Excellence in Leadership: Mary Richt, Hospice by the Sea

Excellence in Program Innovation/Community Outreach: Grief and Loss Puppet Program, Gulfside Regional Hospice

Excellence in Program Innovation-Clinical Practice: Aloesea Program, Hospice by the Sea

The Hospice Story Award: “An Old Fashioned Love Song” by Fred Mortensen, Hospice by the Sea

The Synergy Award: South African Partnership Committee, Suncoast Hospice

The Awards of Excellence program was created to recognize the outstanding and innovative work of individual staff and hospice programs throughout the state. To learn more about this year’s recipients, visit www.floridahospices.org/forum.
UAB School of Nursing Awarded $720,000 to Study Palliative Care by Phone

The UAB School of Nursing (Birmingham, AL) has received a $720,000 grant to fund a four-year study to see if palliative care, when delivered by phone, can help improve the quality of life for Americans with advanced cancer who are living in rural areas.

The grant from the American Cancer Society continues the work of Marie A. Bakitas, professor of nursing, who developed Project ENABLE, a phone-based palliative care intervention.

“Given that advanced cancer patients in rural areas are less likely to benefit from palliative services due to limited access and suboptimal care, we believe this intervention will provide an innovative way for cancer centers in these areas to provide palliative care,” she said.

Bakitas said the study will target four communities representing rural geography and/or ethnic and racial diversity: Birmingham, AL; Grand Rapids, MI; Spartanburg, SC; and Bangor, ME.

Diane Stringer Appointed to Salem State University Board of Trustees

Diane T. Stringer, president and CEO of Hospice of the North Shore & Greater Boston, was one of two prominent professionals appointed by Governor Deval Patrick to serve on the Salem State University Board of Trustees.

Stringer was selected for her large-scale leadership within the non-profit arena. Under her leadership, the hospice has grown from a small volunteer program to one that serves over 3,000 patients annually. She has also been an active member of NHPCO, including service on the board of directors from 2003 to 2008.

“Salem State University,” said Stringer, “is an invaluable asset to the region and Hospice of the North Shore & Greater Boston has had a long collaboration with its schools of social work and nursing. I look forward to contributing to the continued growth and prominence of the university, especially as it strengthens its undergraduate and graduate programs in health and human services.”
S taying up to speed in the ever-changing world of hospice regulations and compliance has never been more essential — but it’s also no easy task.

How We Help
Small but mighty, the NHPCO Regulatory and Compliance team tracks CMS’s proposed rules and transmittals; claims processing issues; interpretations of regulations; the program integrity audits of all contractors, OIG reports and work plans; FI/MAC activity; LCDs and disease requirements; state Medicaid activity; FDA/DEA activity; and more.

Three Ways We Share What You Need to Know
• Regulatory Alerts
These Alerts, which are generally one-to-two page communications, call your attention to essential, late-breaking news. They are emailed to members, with copies also posted in the Regulatory Center of the NHPCO website.

• NewsBriefs
NHPCO’s weekly e-newsletter, NewsBriefs, is another way to learn about timely compliance changes and issues. NewsBriefs is often the only communication about ongoing regulatory issues and is an important source of detailed information. It is emailed to members every Thursday afternoon, but all issues are also posted on the NHPCO website (as PDFs).

• Regulatory Round-Up
This multi-page communication recaps the news that was shared in recent Regulatory Alerts and NewsBriefs, along with links to other applicable resources. It is emailed to members on a monthly or bimonthly basis, depending on need, and all issues are posted on the NHPCO website.

Plus — A Great Search Tool: Regulatory A-Z
The Regulatory Center on the NHPCO website includes the very handy search tool, “Regulatory A-Z.” Like a table of contents, it lists topics in alphabetical order so you can quickly locate what you are looking for.

For example, need information on HIPAA? Just click “H” in the alphabetical list, and you are brought to two links on that topic: HIPAA and HIPAA Version 5010. Select the one that interests you, and you are brought to the respective webpage in the Regulatory Center.
SAVETHEDATE

Pediatric Intensive
Preconference Seminars:
September 24-25, 2013

Main Conference:
September 26-28, 2013

Sheraton and Westin
at Crown Center
Kansas City, Missouri

Innovation
AND
Excellence

14th Clinical Team Conference
and Pediatric Intensive

In Cooperation with, the Missouri Hospice and
Palliative Care Association

I n n o v a t i o n     A N D     E x c e l l e n c e

National Hospice and Palliative Care
Organization

Hospice Action Network

FHSSA

National Hospice
Foundation

Hospice
Manager
Development
Program
Each month, NHPCO president/CEO, Don Schumacher, records a brief video message to alert members to news affecting the hospice community. Sometimes it’s great news such as his April message about the recent research out of Mt. Sinai; and sometimes it is cautionary news, such as his June message with NHPCO vice president of compliance and regulatory leadership, Judi Lund Person.

Bookmark NHPCO’s YouTube Channel for future reference — and be sure to hear Judi’s recommendations from the June video if you haven’t already.