

A Publication of HopeHealth

Touching Lives™

Holding Hands. Holding Hearts.

5 Ways to Support Loved Ones

**Go Ahead – Give
Yourself A Break**

**Finding the
Help You Need**

**Letting Go of
Life's Regrets**

**Why Spiritual
Beliefs Matter**


HopeHealth™
Touching Lives

FEATURE ARTICLE

10 5 Ways to Support Loved Ones

By Kerry Egan



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Welcome to *Touching Lives*



HopeHealth has been enhancing the quality of life for people experiencing serious illness and loss for more than 40 years. Since our early beginnings, we have been focused on helping individuals and families make the most of the precious time remaining in the last months of life. We offer a wide range of services for people with serious illness and their family members, specializing in hospice and palliative care, home health, and services designed specifically for dementia and Alzheimer's caregivers.

Our goal is to help individuals face a serious illness with strength and grace while in a familiar place, surrounded by their loved ones. We are here to help families focus on what matters most to them, alleviate pain, listen to their concerns and do everything we can to make their final wishes come true.

Sharing *Touching Lives* with you is one of the many ways HopeHealth supports families as they experience loss. Read about how to navigate the first steps to starting hospice care in *How to Start Hospice Care from the First Phone Call*. In *Finding Comfort Through Grief Support*, you'll read the story of one young woman's grief journey and the comfort and support she experienced with HopeHealth. One of our wonderful volunteers shares his reasons for volunteering in *The Profound Gifts of Being a Hospice Volunteer*.

The HopeHealth team understands the stresses and uncertainties of serious illness and is here for you. Thank you for your support and we welcome the opportunity to serve you and your family now and in the future.

Warm Regards,

Diana Franchitto
President and CEO



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How to Start Hospice Care

FROM THE FIRST PHONE CALL

Picking up the phone to start hospice care—or even ask questions about it—can be an emotional experience. Kayla Gillis, a HopeHealth referral center and admissions nurse is here to make it easier. “A lot of times people are overwhelmed and they don’t know where to turn, so they just call looking for help,” Kayla explains. “They’re burned out caring for their loved ones and not sure what to do.” Kayla is often the first point of contact for individuals and their families during this vulnerable time.

There are two steps to starting hospice—calling the referral center and setting up an admission visit. How does this process work? Here’s what you should know.

Why people call hospice

Anyone can call a referral center for information. A phone call is not a commitment to start services. It’s usually a spouse or adult child who calls, but a patient may call with questions of their own.

Most people start hospice in the final days or weeks of life, but sometimes people call during an earlier stage of an illness, which can be enormously beneficial for the patient and their caregivers. “We’ve had people on hospice for six to twelve months or more if they continue to meet the criteria,” Kayla explains. There is a common misconception that hospice is solely focused on death and dying, but the care team is dedicated to helping patients achieve the best quality of life during an advanced stage of illness.

The hospice team can help navigate pain and symptom management, medical equipment needs, conversations with family members, and assess needs for services that can include anything from home care, visiting nurses, palliative care, caregiver support and dementia and Alzheimer’s support.

What to expect when you call hospice

When calling a hospice referral line, a referral center representative (usually a nurse) will ask questions about you or your loved one’s condition to understand the best way to assist you. These questions typically concern:

- What is the patient and family’s understanding of the diagnosis and the current status of their condition?
- What medical treatments is the patient currently receiving and what is the desired next step? Is the patient interested in continuing curative treatments or focusing on comfort?
- The patient’s current living situation will be assessed. Some patients may be in a nursing home or hospital, but the team will ask where the patient would like to receive care and try to accommodate what is best for the caregiver and the patient.
- What are the patient’s goals of care? A defining trait of hospice is emphasis on the patient’s wishes and needs. Goals will be discussed at every step of hospice, starting with the first phone call.

How to qualify for hospice

Medicare and most private insurers cover hospice care for individuals who meet these requirements:

- Life expectancy is six months or less if the disease progresses along a typical course.
- The patient has decided to stop curative care and focus on comfort care.
- Two doctors—the individual's primary care physician or specialist, and the hospice agency's medical director—must certify the patient's eligibility to start hospice.

"Whether or not you're eligible for hospice when you call, we can explain what signs and symptoms might indicate the right moment for us to become involved," explains Brian Berger, vice president of access and community engagement of HopeHealth.

The referral center nurse may ask for permission to contact your doctor and get verbal approval for a hospice admissions visit. You or your loved one can also make this request through your own doctor. After the doctor approves, an admissions nurse case manager will visit a patient as soon as possible, often the same day as the call.

What to expect during the admission visit

The admission visit usually takes about an hour.

The nurse case manager will:

- Assess the patient's condition, asking about appetite, weight loss, recurrent infections, recent hospitalizations, and bed sores.
- Review medical records.
- Reconcile medications, which means review the names, dosages and frequency of the patient's medicines and compare that list against their medical record. The nurse will call in a prescription if needed, and arrange overnight home delivery if it is available.
- Explain the types of hospice services available beyond medical care, including social work and counseling, assistance with advance care planning, home health aides, chaplain services, medical equipment (walkers, shower chairs, etc.) and volunteer services like Reiki and pet therapy.

A hospice patient can choose any, all or none of the complementary hospice services, and the admissions nurse will set them up. It is always the patient and family, not the hospice agency, that decides what the care plan looks like.

"Yes, we are going to send a nurse and a doctor," Brian says. "But after that our hope is to make sure that whatever you want this care to look like, that is what we provide. That's why there are all those disciplines involved in your care. Whatever we can do to support the best quality of life, as you define it—that's what we want to do." ❧

Finding the Help *You Need*

It's hard to imagine a time when hospice wasn't an option for every family who wanted a loved one to die with comfort and dignity.

When hospice care was first established in the United States, it was adopted mainly by cancer patients. There was no Medicare or insurance coverage for hospice care, and it was usually offered in the patient's own home.

But times have changed. Today, hospice care is widely accepted as an important level of care for any patient whose disease no longer responds to aggressive, cure-oriented treatment.

Of the 1.45 million Americans now in hospice, most have life-limiting diseases other than cancer, such as heart disease, lung disease, kidney failure, stroke or coma, liver disease, AIDS, and amyotrophic lateral sclerosis (ALS). Hospice care is covered by Medicare, Medicaid, private insurance, and managed care plans.

More families are also turning to hospice care for aging parents debilitated by dementia, including Alzheimer's disease. As they approach the end of their lives, patients with dementia benefit from pain and symptom management, as well as the emotional and spiritual support that hospice provides, while family caregivers get much-needed help caring for their loved one.

In dementia units, a lot of intensive work is done with the families. When hospice gets involved, it's generally in the last phase of their lives, when they are debilitated. The treatment is the same – physical support, social workers, work with the family, and pastoral care.

By Marlene Prost

While most hospice care is still provided at home, that, too, is changing. Americans are living longer with chronic diseases, and many who can no longer care for themselves are moving into nursing homes, and assisted-living and dementia care facilities. That is now their home, which is why 32.8 percent of hospice patients last year received specialized end-of-life hospice care in a nursing facility.

This growth reflects the increased provision of quality care for dying persons who are not in the traditional home setting. For many people, the nursing home is their home, and they deserve the compassionate, quality care that hospice and palliative care providers are trained to deliver.

Compared to similar nursing home residents not in hospice care, hospice patients are more likely to be assessed for pain, twice as likely to receive daily treatment for pain, and more likely to receive pain management in accordance with clinical guidelines. What's more, they are less likely to require hospitalization in the final 30 days of life. ❧

Marlene Prost is a freelance writer, magazine editor and book author.

Getting THE BEST CARE

by Dr. Ira Byock

I've heard too many people say they are worried about what a doctor thinks of their decisions – remember, it is your life.

If you or a close friend or relative has recently been diagnosed with a serious illness, you are probably feeling overwhelmed and vulnerable since treatment options are often complex.

Although you may want to rely only on healthcare professionals for advice, it's important to be prepared to advocate for yourself and your family. As much as I respect my colleagues and am proud to be a physician, doctors exist to serve patients and the public.

Here are some ways to avoid problems and get the best care possible for yourself and loved ones.

Take Control of Decisions

Identify doctors who are experts in your condition and then work closely with your health care team. Although we wish every physician had a warm personality, it is not as important as feeling confident that he or she genuinely cares about your wellbeing. If not, find a new doctor. Feeling comfortable is essential to your care.

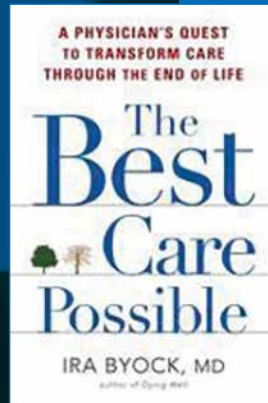
Here are some ways to help you take control and be an active participant in your treatment.



- **Write down questions** you have for your doctor. It can be scary to be seeing a specialist for cancer, memory loss or serious heart, lung, kidney, liver problems. It is not easy to remember all the questions you have had about your medications, symptoms or treatments.
- **Bring someone with you** to doctor's visits to support you and to remember (you may want to record) details of the conversation.
- **Keep copies of your health records** – it is your right to ask for test and biopsy results, lab reports, physician history, reports of physicals and hospital discharge summaries.
- **Keep a daily log of your symptoms and the medications you take.**

Get A Second Opinion

When faced with a dangerous diagnosis, second opinions can be important in getting the best treatments. Use the internet, local experts and word of mouth and don't feel awkward about gathering second – or third or fourth – opinions from the best health care centers and teams.



Do It Your Way

Visit **The Conversation Project** (theconversationproject.org) a national effort to ensure that people's wishes are expressed, known, and honored. Information and advance directive forms are available at little or no cost from sites such as **Everplans** (everplans.com/articles/state-by-state-advance-directive-forms).

Ask About Palliative Care

I strongly advise that one of the medical opinions you seek is with a palliative care physician or team.

Because palliative care grew out of hospice, many people assume that receiving palliative care means giving up. Not true. These days palliative care is provided together with treatments for cancer, heart, lung, liver, kidney and neurological conditions.

Specialized clinical teams work together to minimize pain, increase appetite, help patients sleep better, be more active and feel more comfortable physically and emotionally.

Name A Trusted Advocate

The best way to support one another – and protect one's family from conflict and having to deal with ethics committees or a court – is to make it clear in writing who has authority to speak for you. Make it official.

Give the document to both your doctor and the hospital(s) where you are likely to receive care. Scan a copy of your signed document to share with your health care agent and trusted family members and friends.

Don't Be Afraid to Make Changes

If you don't like or trust your doctor, hospital or medical facility, find a new provider.

Do not feel badly about being disloyal to the hospital you've used for years – this is your life.

Hospice programs provide end-of-life care including managing medical matters and supporting families. You should expect the hospice nurse, social worker and physician to be highly competent, friendly, proactive and responsive.

If the hospice staff seems uncertain, stretched thin, and slow to respond after hours (even though they may be warm and friendly), talk to other hospice providers and ask specific questions.

Remember, at the end of the day, what matters most is getting the best care possible for you and your loved ones. This is no time to settle for less. ✕

Ira Byock, MD is Founder & Chief Medical Officer, Institute for Human Caring of Providence Health and Services. He is an active emeritus professor at Dartmouth's Geisel School of Medicine and author of *Dying Well*, *The Four Things That Matter Most* and *The Best Care Possible* available at IraByock.org.

Go Ahead – Give Yourself a Break

Rejuvenate in ways that feel good

By Paula Spencer Scott

Laura Patyk hated to leave her mother's bedside when she had end-stage congestive heart failure, just as two years earlier, she'd hesitated to leave her father-in-law, who had kidney cancer.

Both elders were in the good hands of hospice programs but it always felt selfish to her to take a break.

"And sure enough, I kept getting sick and developed insomnia," says Patyk, who also cares for six school-age children. "I learned the hard way to take better care of myself, no matter what."

Burnout is a real risk for family members caring for a loved one. Professionals call it "compassion fatigue" – caring so much that you give yourself too little. It's a byproduct of the stress and fatigue that can hamper caregivers, says Patricia Smith, a certified compassion fatigue specialist in Mountain View, California, and founder of the Compassion Fatigue Awareness Project.

"Stress is all about 'too much' – too much work, too much activity, too much stimulus. Burnout is 'too little' – too little time, too little interest, too little energy," she says.

Whatever you call this distressing syndrome, here's a healthier approach:

Be aware that this is a very real issue.

"The premise of healthy caregiving is this: Fill up, empty out. Fill up, empty out," says Smith. "Caregivers who are at risk for compassion fatigue empty out, empty out, empty out. They never learned to fill up so they have something to give."

Warning signs of burnout include isolation, bottled-up emotions, persistent sadness and apathy, lack of interest in self-care, and persistent ailments such as colds or gastrointestinal upset.



Don't think that "nobody can do this but me."

It's true that you know your loved one better than anyone, and you provide a wonderful level of care as a result. But others – family, friends, community resources such as nursing aides and elder companions, or hospice and palliative care teams – can also provide competent, even excellent, care. And their doing so frees you up to refresh and recharge.

Figure out what "fills you up." Give thought to what replenishes you. Walking? Reading? Knitting? Spending time with friends? Being out in nature? Plenty of restorative activities don't cost anything and are always available to you.

Recharge in ways that feel authentic

to you. If your best friend wants to drag you shopping but you find it draining, you won't feel refreshed. Find what works for you, not anyone else. "The art of 'filling up' is finding what brings you peace, well-being, and a sense of belonging," Smith says.

Take technology breaks. There are other sources of stress in our lives that can contribute to burnout. "Because we all love our iPhones, BlackBerrys, iPads, and pagers, we are 'on call' 24/7," Smith says. "Set boundaries. Check your email at 9 a.m., noon, and 6 p.m. only. Limit how much time you spend on your cell phone. Take a complete break from technology on weekends."

Don't be hamstrung by fears of what

you'll miss. Patyk, the Charlotte caregiver-mom, is now caring for her widowed, live-in father, who has cardiac issues. But this time around, she listens to her instincts when she needs a break. She goes bike riding around her neighborhood and lunches regularly with friends. She even recently got away to the beach overnight.

"There's always a little calm even in a storm," she says. "Even if something happened in my absence, I have no regrets because I know I'm doing and saying everything I need to." ❧

Paula Spencer Scott is the author of *Soul-Saving Wisdom for Caregivers* and 10 other books about family and health.

What a Caregiver Needs to Hear

Many caregivers neglect their own needs because they worry what others, including their loved one, will think if they take time away from caregiving.

That's why it's so useful for caregivers to hear encouraging messages of support from patients and the rest of the family.

"You're not selfish."

It may be true that we exist to serve others, but our own bodies also need our attention, to be fed and exercised and replenished. It's not selfishness to divert a little attention from a sick loved one to your own needs; it's being your human self.

"You're not uncaring."

Even in the midst of a crisis, the rest of life goes on. Tending to your own needs momentarily isn't a reflection on the level of love and care you feel for another.

"You're doing us both a favor."

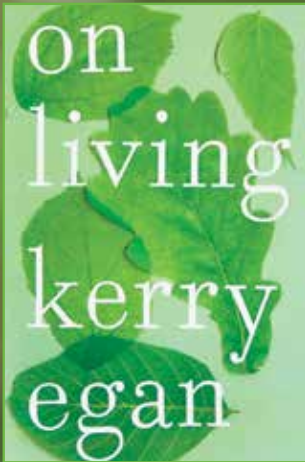
The stronger and more fortified you feel, the better able you are to provide compassionate, meaningful care, and the longer. If you're frazzled and dragging, you won't function well. And that in turn can endanger the comfort and safety of your loved one, which after all is your ultimate goal.





5 Ways to *Support Loved Ones*

By Kerry Egan



The hospice chaplain and author of *On Living* reveals what she's learned about supporting loved ones as they prepare to embark on their last journey.

1 **Many are starved for touch.**

"No one ever touches me anymore," my patient Betty said.

"You can't imagine what that's like." She looked very small on her nursing home bed.

Didn't the aides touch her, I asked, when they took care of her, bathed her and helped her move?

Yes, she said, but it was different. They touched her because they had to, not because they loved her. It wasn't the same.

"I long to be held," she said, and her voice cracked and broke.

What could I do with such a deep, heartbreaking need right in front of me? What would you do? I lay next to Betty, wrapped my arms around her and kissed the top of her head, the way I do with my children when they go to sleep.

Many people who are dying are starved for touch. So ask your friend or family member whether she wants to be hugged. Put your arms around her. Hold her cheeks in your hands. If she wants you to, climb into bed.

2 **They don't need to be told what to do.**

There's a well-intentioned but odd piece of advice floating around out there that friends and neighbors of the dying should show up without calling first and do the laundry or clean out the refrigerator.

Without asking.



People who are dying often feel like they've lost so much control over their lives already. Someone taking over your home without permission can feel like yet another loss to bear.

Yes, offer to help with chores, but don't decide you know what needs to be done. Call first to see if your friend is feeling up to having visitors that day. Set up a time so he can be ready. Ask how you can be helpful.

Dying is exhausting. If the person says he's tired, go home. And if he cancels at the last minute, know that it might be that he feels absolutely awful that day. Don't take it personally. If he says he's overwhelmed by phone calls, believe him, and send a card instead.

3 **They know you are scared, but they still need you there.**

People who are dying are still living. They laugh, and reminisce, and love to see the people they love. They're still who they always have been, even as they go through this new experience.

But they're often crushingly lonely. Too many times, I've heard about the children, the friends, the churches, the clubs who have stopped visiting. "She doesn't need prayers! She needs her friends!" a husband whose wife hadn't had visitors in years once cried.

I get it. I really do. I've had education and training to be a hospice chaplain, and have probably visited over a thousand people who are dying, and sometimes it's still hard for me. Sometimes, the sights and smells overwhelm me. Some people die quickly and easily, but most, at least in hospice, do not. The body struggles to hold on, and it can be really hard to witness.

Someone who's dying often looks different, sounds different, smells different and can't do the things she might have once done. Too often, these changes, and perhaps their own fears of death or saying or doing the wrong thing, make a dying person's friends and family afraid of her.

Can you imagine knowing you're leaving this world soon, needing the people you love more than you ever have in your entire life, and all of a sudden, seeing that they're afraid of you? So try. Try really hard to overcome your fear, and call or visit.

4 **They might not tell you the truth about their feelings.**

"Do you know why you're my favorite?" a hospice patient named Stan asked. "Because you're the only one who will pray that I die this afternoon."

Stan closed his eyes and started again on his favorite pastime: imagining his own death. The scenarios were always different, but what he imagined heaven would be like always remained the same: He'd be walking down a path in a park, and his wife would jump out from behind a tree and yell, "Boo!"

Just as she had 70 years before, on the day they met.

One of the most common things patients ask me to pray for is that they die soon. It can be a huge relief to talk openly about and pray for a quick death, because often their family and friends shush them when they try to.

On the other end of the spectrum, I've had plenty of patients whose families have assured me that their loved ones aren't afraid at all because of family beliefs. And many of those patients, as soon as the family leaves the room, break down in tears, terrified and grateful for the chance to finally talk about their soul-shaking fear.

Never assume you know anything about their spiritual life or feelings. If you want to pray with someone, ask him if he wants to first. Then, ask what he really wants to pray for. There's a good chance you'll be surprised.

5 **They're willing to learn with you.**

Kate, my new friend at the swimming pool, welled up when I told her I was a hospice chaplain. That didn't surprise me; it's a common reaction if someone's used hospice for their family before.

"The nurse gave us this booklet that explained what would happen as Mom died, and it all happened exactly the way the pamphlet said it would!" Kate said as tears slipped from her eyes. "It was totally accurate!" Her voice caught in her throat.

I was confused. Hospice nurses give out these booklets to comfort families, to assure them that what they are seeing

and experiencing is normal. Why did it have the opposite effect? Why was Kate so upset?

"How did I not know this?" Kate continued. "How did I get to be 45 years old and not know that this is how people die? That it's so well known they can predict it? It just seems like something I should've known!"

We don't see death up close very often in our culture anymore, and most people have little or no experience navigating it, so it's normal not to know how it usually happens, and that there are steps and stages to it. Add in the fact that you might already be grieving for your loved one even before he or she is gone, and it's a recipe for confusion and regret.

It's okay that you're not an expert in dying. The person who is dying has never died before either. You can muddle through this process together.

Hospice patients are surrounded by aides, nurses, social workers and chaplains who do know what they're doing. Ask them for advice and information. Don't be ashamed of being nervous or overwhelmed. Not knowing what you're doing is not a reason to stay away.

What people who are dying really need is to be surrounded by the people who love them, even if those people have no idea what's happening. Your loving presence is the greatest thing you can offer someone. You don't need to know anything to do that. ✕

Kerry Egan is a hospice chaplain and the author of *On Living*.

Share Your Life Stories

by Kerry Egan, hospice chaplain

No matter how you feel about a life limiting diagnosis, I want you to know that you are precious, and the story of your life is precious. There is a universe of wisdom in the story of every person's life, if we would only listen to each other and to ourselves.

So find someone who will listen – it could be your chaplain, social worker, nurse, aide, or your volunteer from hospice. Or perhaps it's a dear friend, or a beloved family member. Find someone you can trust with the enormity of your life's stories, the joyful and terrible events and tiny details that mean everything to you.

I know your stories are there, waiting to be told, because no one has ever said to me, "You know what? Nothing really happened in my life." Not a single person. There is a story, and great value to be found in every life.

If you can't share your story with another person, for whatever reasons, tell yourself, or tell your God. Because this is how people find the meaning of their lives: by remembering the events they experienced, the things they created, and most importantly, the people they love and have been loved by.

Why Spiritual Beliefs *Matter*

By Harold G. Koenig, M.D.

According to research, people who have a faith in God believe that nothing is random, that all things have a purpose, and that no situation exists that God cannot use for good. Interviews with people who are experiencing disabling, life-threatening, or terminal illnesses report that religious beliefs are frequently used to cope and the majority say that this gives them meaning and peace.

Even the archenemy of religion, Sigmund Freud, said that “... *only religion can answer the question of the purpose of life. One can hardly be wrong in concluding that the idea of life having a purpose stands and falls with the religious system.*” The scientific worldview sees life as having no ultimate purpose or meaning, but only a freak accident resulting from random forces of nature.

Research has also revealed that those who are more religious have more hope and are more optimistic. While atheists may call this hope “delusional” and such optimism “unrealistic,” they will never be able to prove their points since no one will know the answer to that question until they cross over the threshold of life – when it will either be too late or it won’t matter.

The person of faith, though, will possess the delight of hope and the joy of optimism during the remaining moments of his or her life,



something that the unbeliever may never experience, prevented by dependence on and trust in the rational mind.

When confronting death, a natural response is fear – fear of the unknown, of the ultimate loss of all control. Religion helps people to deal with that fear. In the Christian tradition (but certainly not limited to this particular faith) is a scripture that says, *“love casts out fear.”* What is the love that casts out fear? The love that casts out fear is the love of God and the love of people.

First, is the love of God.

Loving God means trusting God with all the unknowns and unfathomable situations in life, including death. Trust in God means believing that when we stand at the precipice of death and must take that step into the unknown, that God will be there to catch us in his arms and carry us to safety.

The belief that God is real

outweighs any fear and concerns of what might lie on the other side, and the trust we have that God will protect us completely nullifies whatever fear we may have of the unknown.

Those who have known God in life have nothing to fear in death, for the one who loves them is waiting to greet them.

Second, is the love of others.

This love also casts out fear and gives purpose and meaning to those who are dying, and so is essential to a good death. Religious teachings and rituals surrounding death help make the transition easier for the dying person and for the family that is left behind. These sacred rituals connect the dying and the living to the life that extends beyond this life, and helps all to say goodbye. That farewell, however, is only a temporary one.

Faith is what guarantees that there will be a time of reuniting and celebration beyond the grave.

Most religions have beliefs and rituals that make possible the forgiveness of sins committed during this life, and provide an opportunity for the forgiveness of others. That forgiveness helps to heal the wounds inflicted on the dying person and by the dying person on family and friends, and minimizes the pain of separation and the regrets and sense of loss that family and friends are left with after a person's death.

A good death should be one without regrets where the dying person has done everything possible to leave this earth with a clean slate and leave others with a clean slate as well.

Those with faith, both the dying and the living, then will say “I love you” and “farewell for now” – each person leaving the other in the care of God, the comforter behind the door that all will someday walk through. ☘

Harold G. Koenig, M.D. is the Director of the Center for Spirituality, Theology and Health at Duke University Medical Center, Durham, NC.

Letting Go

of Life's Regrets

By Beth Carlton



As a palliative care nurse/counselor caring for terminally ill patients, Bronnie Ware asked her patients if they had any regrets they wanted to share about their lives and anything they would do differently if given the chance. In her book *The Top Five Regrets of the Dying*, Bronnie shares the most common regrets expressed at end of life:

I wish I had pursued what I wanted, rather than expectations

The most common regret was about not honoring one's own dreams and making choices based on what others expected.

I wish I had not worked so hard

Expressed by every male patient, Bronnie asked what they would have done differently. Most believed that a simpler lifestyle and better choices would have allowed them to be happier and spend more time with loved ones.

I wish I had the courage to express my feelings

Many people suppressed their feelings to keep peace with others which often resulted in resentment. It's never too late to be deepen mutual respect and healthy relationships by

communicating kind, honest and constructive feelings.

I wish I had stayed in touch with my friends

Many had become so focused on their own lives that they had let friendships fade away. Often patients try to reach out to family and friends to restore relationships that were meaningful to them.

I wish I had let myself be happier

This is a surprisingly common one. Many did not realize until they were nearing the end of their lives that happiness is a choice. They had stayed stuck in old patterns and habits. Fear of change had them pretending to others and to their selves that they were content when deep within, they longed to laugh and be light hearted again.

Although we cannot change the

past, there are things we can do today to enhance our lives.

- Apologize for the things you regret and ask for forgiveness.
- Be willing to forgive yourself and forgive others.
- Fix what can be fixed and let go of what cannot be changed.

Talking with someone about these feelings – a partner, a dear friend, a spiritual advisor, someone you trust – can help process these feelings so that they no longer feel painful. It may take many tries but eventually many patients feel the burden lifted by coming to terms with their life regrets.

According to Bronnie, nothing else mattered to her patients in the final days of their lives but love and relationships. ❧

Beth Carlton is a freelance writer who specializes in health care issues and end-of-life care.

Finding Comfort

Through Grief Support

Yostena Makram didn't have time to prepare to say goodbye to her beloved sister, Ireny. Ireny passed away suddenly after being diagnosed with advanced cancer. The loss was devastating, and Yostena's grief was long and complex. But, she got through it with help from HopeHealth.

Before Ireny passed, a HopeHealth hospice team member gave Yostena a grief support information packet. "They told us that any kind of support our family needed would be found inside," she said. "At the time, I had no idea how true those words would be."

She took the packet home and moved it from counters to drawers for several months before finally deciding to call HopeHealth for help. "I didn't know what hospice support would look like, but I knew we needed help grieving, talking, communicating. I couldn't rely just on myself or friends," she said.

After calling HopeHealth, Yostena was paired with grief support manager, Diane Lambert. Grief counselors have special training in helping people heal from the death of a loved one. She attended a grief support group designed specifically for people who have lost siblings. She said the group made her feel like she belonged. "Our losses may have looked different—younger, older, sudden illness, lengthy—but we shared feelings that I had not been able to put into words."

Yostena continued working with Diane and the support group, and she was pleased to discover she could try



Yostena Makram

different grief services offered by HopeHealth. "The doors are always open, especially as your needs, emotions and grief evolve," she explained. Yostena began attending mindfulness meditation classes and her engagement with grief support didn't stop there.

Yostena attended HopeHealth's Weekend of Hope & Healing, an adult grief retreat, and has continued to do so for three years. "I was anxious about attending

so soon after my sister passed away. I knew that it would be an important experience." The retreat has become an annual pilgrimage for her.

Just a year after Ireny passed away, Yostena participated in a remembrance event called Light Up a Life. She found it both challenging and helpful to share her feelings at this event. "I didn't realize how important it would be to speak about my sister, to say out loud that I am here because I love her and I lost her. That grief is part of my journey, but HopeHealth has helped me stay grounded."

The support Yostena found through HopeHealth helped her get through the death of her mother in 2018. She would encourage anyone who has lost a loved one to ask for help. "On the days that seem impossible, HopeHealth is always there. Through HopeHealth, I learned that I could get through this, that I owed it to myself and my family to hold on to the people who want to help."

To learn more about HopeHealth's grief support services call the Center for Hope & Healing at (888) 528-9077 or visit HopeHealthCo.org/Grief. ❄️

The Profound Gifts of Being a Hospice Volunteer

By John Corvese



John Corvese

As a hospice volunteer with HopeHealth, I visit patients who are approaching the end of life. They may have cancer or heart disease, kidney failure or dementia. When people learn what I do, they most frequently say, “Oh, I don’t know how you can do that. I certainly couldn’t.”

Death and dying, we don't speak about that much, do we? It's sort of like politics—not the kind of topic we talk about in polite conversation. I'd like to tell you about something that happened to me not too long ago. I was making an initial visit with a patient—I'll call him Brad because we keep all patient information confidential—who had just come into our hospice program.

Typically, the first visit is where I talk about what I do. The patient and I get to know each other in an effort to decide if we're a good match. After I told Brad everything I could offer him, he asked me what my compensation was, which startled me. "I don't get paid anything, I'm a volunteer," I said.

Brad stopped for a moment, then asked, "Why do you do this then?"

I didn't respond right away. I think my eyes might have glossed over and I asked myself, why do I do this?

It's about the patients and families. I've had the honor of speaking with mothers, fathers, grandmothers, grandfathers, and family friends. They have all told me their stories. I get to connect with people.

I've had the privilege of talking to veterans. They tell me stories about the horrors of war and the humor of boot camp.

I have gently held the crippled, badly misshapen hands of a 92-year-old woman with severe rheumatoid arthritis, while her left knee is locked in a bent position. Whenever the nursing home staff repositioned her, her eyes would fill with tears from the pain.

When she was well enough to live at home, she loved hearing the birds sing at the feeders in her yard. Since there were no bird feeders at the nursing home, she and I looked at photos of birds together and listened to them sing on a smartphone.

I have helped a man write the epitaph for the grave of his dear wife who preceded him in death the year before. He wanted to finish it before he died, and his words were precious.

I have sat with a man in the final stage of Alzheimer's disease. He couldn't feed himself and had trouble controlling his movements, but he loved Neil Diamond's music. So we put on a CD and listened to endless Neil Diamond songs. Hearing the music, this man—whose

memories of life and family were forever lost to him, whose mind and body were rebelling against him—would close his eyes and tap his feet and nod his head in time to the music, a smile appearing on his face.

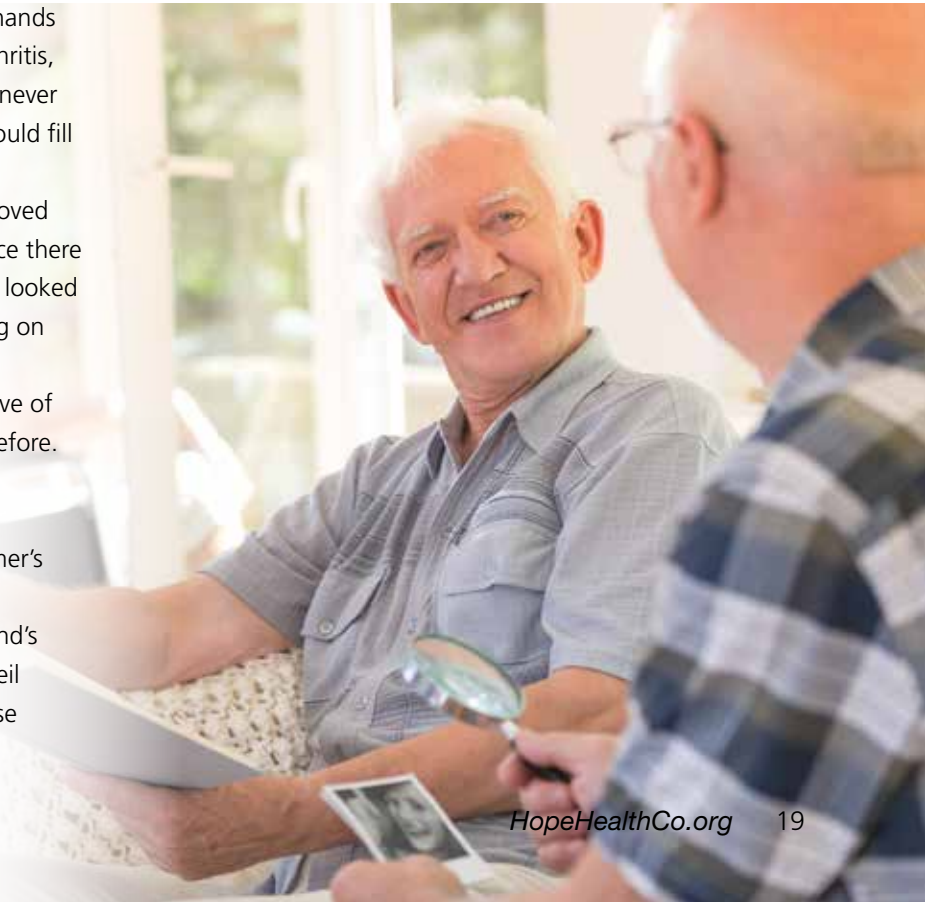
When I volunteer, it also helps me remember my own family members who were on hospice care at the end of their lives. My aunts, Rose, Lil and Joyce. My grandmother, Marie, who was "Memere" to me for all my years. My father, Bill, and my mother, Loretta. They all gave me so much, and took so much of me with them when they died.

I am also inspired by the people at HopeHealth—the coordinators, managers, doctors, nurses, social workers, bereavement counselors, spiritual counselors, certified nursing assistants, office people and volunteers. They motivate me through my own experience with my family and on my new path as a volunteer.

All of these thoughts occupied me as Brad waited for me to answer. Finally, I shook off my stupor and saw him staring stone-faced at me.

"I don't have words to answer you," I replied, "But I can tell you that what I do touches my heart."

Brad's expression softened. He smiled and said, "That's a good reason." ❧



“ When my dad got sick, we wanted to take care of him at home. We were referred to HopeHealth by the hospital. When my dad arrived home by ambulance, we were met by fabulous people who assured us this was the best decision for him. They were the most passionate, caring group of professionals, who answered every question we had. They handled all the important issues so we could be there to take care of my dad. Supplies and medications were all taken care of, and we were instructed on what to do. They kept my dad at peace, retained his dignity to the best level possible and kept us all sane. They took a lot of the burden away from us. To have help from people who understand and are compassionate and are there to work with you is a blessing. HopeHealth is a great organization, and the staff is awesome! ”



*Cheryl Hulslander
HopeHealth family member and caregiver*

HopeHealth is dedicated to touching lives in so many ways.

When you are facing serious illness or loss, hope is here. HopeHealth has been enhancing the quality of life for people experiencing serious illness and loss for more than 40 years. HopeHealth provides compassionate and high-quality care when you, or someone you love, is diagnosed with a serious illness. Whether you need hospice or palliative care, home health care, or specialized services for dementia and Alzheimer's, HopeHealth is here to help you.



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HopeHealth Hospice & Palliative Care is The Major Teaching Affiliate for Hospice and Palliative Medicine
of The Warren Alpert Medical School of Brown University

