Family support
How hospice helps the family navigate the final voyage
Caring for patients and families

Our Compassus colleagues are dedicated to providing exceptional care to your loved one and family. Those two words — “and family” — are key to our vision. Hospice is much more than pain and symptom management for someone with a life-limiting illness; hospice helps guide family members through a journey they likely didn’t foresee and would rather not take. Hospice is there to share the load — physically, emotionally and spiritually — and help the family find comfort.

As longtime hospice professional Johanna Turner says in our cover story, when we’re overwhelmed, faced with the impending death of a family member, we reach for those most dear to us. “Families are our safety nets and sources of strength,” she writes.

Indeed. The diagnosis of a life-limiting illness reaches beyond the patient to include those who love him or her most. That’s why our singular goal is improving quality of life for patients and their families with professional support provided by an involved and caring team.

This family-centric approach, as Johanna Turner says, can help families tap into their unique resources for navigating their loved one’s final voyage.
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Hospice is much more than nursing care for someone with a life-limiting illness; it involves a family-centric approach to ensure that physical, psychological, social and spiritual needs are met for the patient and his or her family.

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Retired teacher once again delights in the musical sounds of children

By Marcia Winn

As a teacher, Justine spent a good part of her life around children. So when Heidi Dube, RN, case manager for Compassus in North Andover, Mass., learned a nearby elementary school was planning an end-of-year concert, she thought Justine might like to return to the kind of place where she’d spent so many years.

After contacting administrators at Great Oak Elementary School in Danvers, Dube made arrangements to transport Justine to the event. Staff members and teachers were on hand to welcome her warmly as a special guest. Taking a place of honor next to the superintendent of schools, Justine reveled in being around students once again as she listened to the chorale group and band perform lively renditions of favorite songs.

Happily, Justine’s special visit rekindled a lost tradition at Great Oak Elementary. The previous music teacher often took small groups of students to the nursing home where Justine now resided, but that practice ended with the death of that teacher. Now the school plans to resume the tradition of bringing music to the nursing home’s residents.

This meaningful outing illustrates how our entire care team remains committed to finding and nurturing opportunities to enhance the welfare and to maintain, as much as possible, the essential elements of our patients’ lifestyles whenever we can. 😊

Marcia Winn is a social worker for Compassus in North Andover, Mass.
Physician Spotlight

Shining a light on doctors who serve hospice patients

Dr. Alyson Emmons helps solve ethical dilemmas

One of Dr. Alyson Emmons’ hospice patients was requesting that her ventilator be removed, which most assuredly would lead to her death. But the patient was in deep depression, raising the question of whether hers was a right-to-die situation or a suicide.

“This was a very difficult case,” Emmons says, “deciding when someone is letting depression interfere with their decision making.”

Another family doesn’t want their elderly mother to know she is dying and wants their medical team to keep the secret. “What do we do?” Emmons asks. “Is that ethically allowable?”

Such dilemmas occur every day and are among the important and delicate issues that patients and families raise.

As a recent appointee to the Compassus Medical Director Advisory Council, Emmons, a doctor of osteopathic medicine, will help Compassus navigate those dilemmas which, in turn, will benefit patients and families.

The advisory council’s 12 members set an example for the company’s 230 medical directors. They serve as a resource and provide guidance on policies and best practices. Emmons will serve a three-year term on the board.

“Ethics in hospice care is one of things you’re not really taught in medical school,” Emmons says. “As time went on, I found I was being confronted with situations I was not trained to handle.”

Most doctors who began practicing more than a decade ago were not trained to handle ethics-related situations, including when it’s time to stop treatment, she says.

Doctors are committed to saving patients, so they don’t stop curative treatment until the very end.

“Many of them see hospice as giving up on a patient,” she says.

Consequently, many patients come to hospice too late, giving them and their family only a week or two to prepare for their death. Emmons, an internist, is working to change that.

“I love internal medicine, with how exact and precise things are,” she says, “but what I love about hospice is I feel I can really make a difference, helping people at a critical time and that maybe is more important than my other job.”

Emmons works for Gericare, the geriatric branch of Advocare, in subacute rehabilitation at Virtua Memorial Hospital in Mount Holly, N.J. Prior to that, she worked as a hospitalist for five years for Advocare in New Jersey for Virtua at the Marlton and Voorhees campuses, and in emergency room medicine.

She graduated from Philadelphia College of Osteopathic Medicine in 1996 and specializes in internal medicine. She added hospice care to her practice in 2010 and is board certified in Hospice and Palliative care since 2011.
LOVE AND CHICKEN SOUP

By Synthia Cathcart, R.N., B.S.N.

A comedian once told his mother he had only a short time to live. Upon hearing the distressing news his mother said, “Sit down, and I’ll make you some chicken soup.” The man asked, “Do you really think that will help me now?” His mother responded with a hopeful smile, “It couldn’t hurt.”

Many caregivers for terminally ill patients feel much the same way. Because food is symbolic of love and nurturing, it is extremely difficult for family members to see their loved one having no desire or ability to eat. A common reaction is to want to begin using nutritional supplements, tube feedings or even I.V. nutrition with the idea, “It couldn’t hurt.”

For patients with tumors, feedings may provide more nourishment for the tumor than the patient, which may actually shorten the patient’s life expectancy.

Forced feeding with oral supplements or tube feedings can increase the patient’s gastrointestinal distress, causing increased suffering.

Serious infections are often an occurrence associated with the use of I.V. nutrition.

True weight gain with these methods is marginal. The gain is usually attributed to fluid retention.

When caregivers see their family member eating less or eating nothing at all, it is often the first time they face the realization that their loved one is going to die soon. If they can keep the patient eating, “He will live longer, right?”

It is difficult for loving family members to understand that by pressuring or forcing a patient to eat, death won’t be put off and the suffering may be increased. But this does not mean there is nothing that can be done when the patient’s appetite begins to decrease.

WHAT YOU CAN DO

It is helpful to offer small, frequent meals, and if any supplements are added, the homemade varieties are best tolerated. Puddings, gravies, soups and milkshakes can be made with whole milk, which has been fortified with powdered milk.
Hard candy helps to moisten a dry mouth and add calories at the same time. Medications to control nausea and vomiting may be helpful in allowing the patient who desires to eat, to do so as comfortable as possible.

However, in spite of all the interventions, there will come a time in most terminal illnesses when a patient no longer feels any desire to eat, and, in fact, may be repulsed by food. When this occurs, no matter how upsetting to the family, the patient should not be pressured or forced into eating.

Caregivers should understand they are doing the right thing for their loved one by not insisting on artificial nutrition. Caregivers also should realize their loved one is not becoming too depressed to eat, nor is the patient trying to commit suicide; this decrease in appetite is part of the terminal process.

The issue of nutrition is probably one of the most guilt-inducing, frustrating and emotionally charged issues with which terminally ill patients and their families must deal. But with the help of hospice, both the family and the patient can make informed decisions based on what is best for the patient, allowing the patient to live and die as comfortably as possible.

What is best sometimes means to HOLD THE CHICKEN SOUP and substitute LOVE.

Synthia Cathcart, R.N., B.S.N., is vice president for Clinical Education and Development at Compassus.
There are two undeniable, unavoidable natural facts of life. We all are born. We all will die. There is no surprise in either event, yet for many years both were hidden away. Medical professionals made the decisions about life’s beginning and life’s end. Then families reclaimed their right to have childbirth reflect their own wishes and values, and it changed the standards of good obstetrical care.
Back in the 1960s and ’70s, mothers and fathers had some new ideas about childbirth. Moms decided that they didn’t want to welcome a new life into the family all by themselves; it should be a family affair. Dads decided that they didn’t really want to sit out in a waiting room, worrying about the person they loved most; it should be a family affair. So from the very beginning of the pregnancy, mothers and fathers talked about how they wanted the birth to happen.

Where did they want to be — at home, in a birthing center or in a hospital? Who did they want to be with them? What kind of medical treatment did they want to keep mom comfortable? They talked to the obstetrician about their wishes and got advice on the medical aspects of their plan. They learned all they could about childbirth; they got rid of any fear of the unknown. When the time came for the baby to be born, they were confident that they could handle anything together, and their doctor knew exactly what they wanted. It was going to be a family affair.

**HOSPICE EMERGES**

The late 1970s and ’80s introduced hospice care, which focuses on the other of life’s two expected events. Similar to the evolution of childbirth customs, hospice brought families like yours back into the picture.

You and your family are probably facing some challenging health care decisions. It may be hard for you to talk about death or know what to do next. Perhaps you feel alone and like you are losing control. Maybe you are confused by the information you are getting. Medical interventions happen before you have a chance to understand them, and you are probably worried about money. It is unclear who is in charge — but it certainly doesn’t feel like you are.

**SAFETY NET**

When we feel overwhelmed, we reach for what we know best and what is most dear to us. Families are our safety nets and sources of strength. It is good to know that hospice care can help you tap into your family’s unique resources for navigating the final voyage of life — much as those childbirth pioneers empowered families years ago.

Hospice programs help family members understand, prepare for and support each other through a final illness. With sound medical advice, hospice helps families make the choices that are right for them. It teaches family members how to confidently give the best care possible. When death comes, hospice continues to care for family members in their grief. Hospice is now the standard for excellent care at life’s end.

How do families and hospice programs work together? A Family Strengths Model suggests there are six clusters of qualities exhibited by strong and loving families:

- Commitment
- Togetherness
- Appreciation
- Good communication
- Spiritual well-being
- Coping with crises and stress

These qualities are also part of the hospice concept. Hospice exists to help family members keep their commitments to each other when a loved one is dying. Your commitment

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1 The Family Strengths Model; Stinnett and DeFrain 1985; DeFrain 1999
could be to keep the patient at home rather than in a hospital or nursing home (although hospice care can happen anywhere); to be at the patient’s side; or even to mend a relationship.

Certainly, one commitment would be to ensure the best of care. Hospice professionals make this possible. Knowledgeable nurses are hands-on clinicians as well as the communication bridge to physicians and other health care providers.

Hospice care depends on your family members coming together, each doing their part. The hospice staff does not “take over;” rather, they teach and support. You and other family members can give amazing care, thanks to the experience shared by hospice nurses.

When this togetherness seems like a tall order under the stress of serious illness, that’s where help with communication comes in. Family meetings, often led by hospice social workers or nurses, can help you all talk about your feelings, cope with the impending death and make the decisions that are right for you.

Hospice workers recognize that no one knows the patient better than you and your family. Hospice appreciates the abilities and skills of each family caregiver and helps you appreciate each other during trying times. Hospice also supports you in saying goodbye to the one who is dying, conveying love and gratitude in your own way.

Religious traditions and personal faith can play an enormous role in a patient’s physical and emotional well-being, as well as your own comfort, as death approaches. Faith often provides a meaningful context to life and to death. Hospice honors the spiritual dimensions of every family. A chaplain is available to meet your family’s spiritual needs or serve as a connection to community clergy of your choice.

In moments of medical crisis, you can be confident that you can reach a hospice nurse 24 hours a day and get a prompt response. When stress mounts, hospice staff and volunteers provide practical assistance and assist you in finding the help you need. Focused support during grieving lasts for many months after the death occurs.

If money concerns increase stress, it is good to know that hospice care is covered by Medicare, Medicaid and virtually all other insurance plans. And if there is no insurance and resources are limited, hospice care is offered on a sliding scale. The most important thing is that your family has the opportunity to care for your loved one according to family wishes, and that he or she lives out those final days in comfort and peace.

Remember that death, like birth, is part of your family’s unique story, and that your values and choices make all the difference. Hospices exist to make it a family affair — your family’s.

Johanna Turner is a retired 35-year hospice professional. Reprinted with permission from the American Hospice Foundation.

To learn more or talk about how hospice can work with your family, visit Compassus.com/locations, browse our state-by-state location list and call or complete the on-page form.
ON TOPIC  NATIONAL POLICY FOR CAREGIVERS

THE “RAISE” FAMILY CAREGIVERS ACT
PASSES INTO LAW WITH BIPARTISAN SUPPORT

HOSPICE FAMILIES
get a helping hand from U.S. lawmakers

U.S. Senators Debbie Stabenow (D-Mich.) and Shelley Moore Capito (R-W.Va.) share why they recognize and endorse an important new law that supports family caregivers.

Family caregivers are a vital part of any patient’s life. They prepare meals, manage medications, help with bathing and dressing and do so much more so that their loved ones can live at home and be independent. The Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, which I co-sponsored, supports caregivers by identifying their needs earlier in the care-planning process so that they are given the support they need to help their loved ones.

Thanks to strong community partners like Compassus, as well as the work of patients, family members and caregivers, we passed the RAISE Act into law earlier this year. Compassus does such important work by providing hospice care to people who are nearing the end of their lives and who deserve to live every day with dignity and compassion.

I will continue working to make sure family centered care is a priority and that everyone who wants hospice care can access those important services.

– U.S. Sen. Debbie Stabenow

Supporting family caregivers is a very personal priority for me. Having cared for my own parents, I understand the unique and important role families play in caregiving. Not only is it truly a full-time job, but it’s also one that very often takes an emotional toll.

That’s why I think it’s so important that we do what we can to provide caregivers the support they need. One of the ways I’ve worked to do that is through my Recognize, Assist, Include, Support and Engage Family Caregivers Act.

This legislation, which President Trump signed into law in January 2018, establishes a national strategy to support the more than 40 million family caregivers in my home state of West Virginia and across the country. Caregivers do so much for their loved ones, and it’s important that we recognize and support the vital services and compassionate care they provide.

– U.S. Sen. Shelley Moore Capito
COURAGE OVER FEAR
HELPING PARENTS FACE THE DEATH OF A CHILD

Providing hospice care to the littlest patients

By Jackie Bustamante

Certain words instantly trigger fear: life-threatening, serious, terminal illness, suffering, pain, death and dying. And when those fearful words refer to a child, anxiety is multiplied.

Fear is why many hospices do not accept children into their program, with such explanations as, “we have never done that before,” “it would be too hard on our staff” or “we aren’t trained to provide care to children.” Unfortunately, this leaves a population of seriously ill, often terminal children and their families with no providers in the area they live.

Fortunately, some hospice programs reject fear and embrace the courage required to provide hope, peace, comfort and strength to face the worst fears imaginable: death of a child.

The Compassus staff serving Columbia, Jefferson City, Macon and Osage Beach, Mo., doesn’t shy away from these scary situations. We move forward with courage for children and families in need.

Often we are asked to go outside of our service area to provide care to children, because no other agency will. We have faced the challenges head on by educating and training colleagues, learning as we go, and facing our fears with courage.

As a result, children and families clearly benefit from the opportunity to have care and support during such a poignant time in their lives. It isn’t always easy — just like our adult population isn’t always easy — but it is worth it to make such a difference to those in need.

We are proud to choose courage over fear. We salute the patients, families and caregivers who face great fears with a courage and inner strength we often didn’t believe possible.
Lucy: A Sweet Blessing

Lucy is a cute baby girl with loving parents and sisters. For the first eight weeks of her life, she lived in a hospital more than an hour away from her home.

Her family spent as much time with her as possible. Lucy’s mom stayed at the hospital for days at a time, away from her other daughters and husband. Lucy’s dad needed to work and visited her as often as he could. Her sisters, Layla, 14, and Jenevieve “Jenna,” 2, would visit when possible but mostly stayed with supportive family members.

Lucy wasn’t expected to live past birth; only 10 percent of babies with Lucy’s diagnosis live to be a year old. A concerned physician talked with Lucy’s parents about how difficult it would be to care for her at home, both physically and emotionally.

Physically, she has lots of needs — medical equipment, frequent medications, feedings and oxygen. The physician expressed concern that Lucy’s family, especially her sisters, might struggle emotionally with having her home because they would become attached and Lucy’s life expectancy is short.

Lucy’s parents considered those concerns and concluded that the whole family was already attached to and loved Lucy. This little baby is a big, important part of their family. Mom and Dad decided Lucy and her sisters would all do much better at home where they are surrounded by family and able to spend quality time together.

“I believe in the power of love,” Lucy’s mom said.

The family was told about hospice services and Compassus was blessed to receive a referral to help care for this special baby and her family. We strive to provide quality of life care together, as a team, with Lucy and her family.

Each family and its needs are unique. Hospice can make a positive impact by listening, encouraging family involvement, providing honest answers that help families prepare and advocating for the needs of patients and families. As a hospice social worker, assessing the needs of the family and discussing their goals and hopes helps identify what the family will find helpful and meaningful. It was important for Lucy’s family to be able to create memories with her.

One of Mom’s goals was to have family photos taken. I located a local photographer who was willing to donate her services. Lucy’s mom also expressed she would like to make an ornament for their Christmas tree with Lucy’s fingers as little snowmen, just like Layla and Jenna had made when they were younger.

Other memory-making projects included fingerprint charms, clay impressions of Lucy’s hands and feet, and handprints in paint of the entire family. These are all meaningful keepsakes they will treasure.

Meeting families where they are — mentally, emotionally, spiritually and physically — can make a world of difference during the challenges they are facing. What a blessing this sweet baby and her family are to our hospice!
Greg was 56 and married to Jane, the love of his life. He had always wanted to be a pilot, but he developed a seizure disorder, so the license would never be granted.

Their's was a true romance. They would host movie nights in their back yard and project old films onto a sheet they stretched across their garage door. They spent years renovating their bungalow together, with Greg executing Jane's designs, right down to her smallest whims.

Everything changed almost two years ago when Greg suffered a stroke and lapsed into a coma for a few days. He slowly came out of it and doctors told Jane he had an 80 percent chance of recovery.

Greg had always made it clear he didn’t want to be on a ventilator or continue living if he were severely disabled, but because he was young and strong, Jane and their son could not give up hope that Greg would recover, so he was placed on a ventilator.

Greg eventually was weaned off the ventilator, but his improvement was limited and his disability severe. Greg’s speech was impaired. He was paralyzed on one side. He required a feeding tube, and he had a tracheotomy.

Greg impressed upon everyone who would listen, in any way that he could think of, that he did not want to live like that anymore.

Greg came onto hospice services, and Jane had many long conversations with her Compassus care team. Finally, just after Greg’s 57th birthday, Jane and her son decided to honor Greg’s wish to stop artificially prolonging his life.

His decline was gradual, and he remained alert and able to connect with the many family members who came to say goodbye. Jane would lie next to him in bed, or sit at the bedside with her head resting on his chest. They held hands and spoke to each other with their eyes.

Jane spoke to Greg about what his passing might be like. He had an older brother who had died when Greg was 16 and she told him his brother would be there to welcome him. When it was her turn to die, she told him, she wanted Greg to come welcome her and to “come pick me up in an airplane.”

Greg passed peacefully, taking his final breath with Jane at his side, holding his hand while their wedding song was playing.

They never felt alone, or judged, and they trusted us to travel down this very painful path with them. Jane truly walked her husband “home,” but as a hospice provider, Compassus helped to carry them when their burden was too great.

Michelle Rutigliano is a social worker for Compassus in Wall Township, N.J.
Make a difference as a hospice volunteer

Volunteers interested in assisting hospice patients and their caregivers can help in three areas that offer a wide variety of tasks and activities.

**PATIENT SUPPORT**

Patient support volunteers provide companionship to the patient and relief for the caregiver. Ways to help include:

- Friendly visits
- Writing letters
- Reading to patients
- Light housekeeping
- Running errands
- Meal preparation
- Hair care

**BEREAVEMENT**

Bereavement volunteers support families and friends of deceased patients. During the grieving process, the volunteer is an invaluable resource, especially for those who lack a solid support network. Ways to help include:

- Assist with grief support groups
- Coordinate community resources
- Help Bereavement Coordinator write letters or make calls

**ADMINISTRATIVE**

Administrative volunteers help the hospice staff, often by working in the office. Ways to help include:

- Sending birthday cards, sympathy cards and bereavement notes
- Assisting at community workshops
- Coordinating support services
- Making deliveries
- Typing, filing and other light office work

www.compassus.com/volunteerform
FORKS IN THE BED

By Karen Robertson

Stopping by his mother's house one evening, my husband was met at the door by a very upset caretaker. “There are forks in the bed!” she exclaimed, “and knives, too!”

My mother-in-law had suffered a stroke, which left her bedridden and totally dependent on others. She was blessed to have a hospice team tend to her medical and spiritual needs, local sitters who managed the daily tasks of bathing and feeding and family who visited often and loved on her in every possible way.

But even with this support group, her health slowly declined and we saw her world shrink from her large house to a single bedroom.

But forks in the bed? That was a new situation. After listening to the caretaker, my husband checked and indeed found several forks and a dinner knife tangled up in his mom’s bed covers. He learned that earlier that day his mother had remembered her beautiful silverware stored in her china cabinet. She had asked the morning sitter to bring the utensils to her bed where she spent the day happily examining her treasured flatware.

Laying each fork and knife out on her bedspread, she admired the engraving and recalled happier times and special occasions. During the day some of the silverware slipped down in the sheets, undiscovered until the evening sitter found them. My husband chuckled and reassured her the silverware posed no danger and returned it all to the china cabinet.

The next day my mother-in-law was still talking about her flatware. Once again, I brought the forks and knives to her bed and listened as she told me their history. Suddenly, I was hit with inspiration.

“Mom,” I asked, “why don’t you use some of your silverware to eat with every day?” She was delighted with the suggestion and her sweet caretaker began serving her simple meals in grand style, allowing her to enjoy possessions previously packed away and forgotten.

As I watched her enjoy something as simple as a fork, I realized that because she could no longer walk through her own house to admire things — her framed needlework, a soft afghan draped over her sofa, a framed photo — it was up to us to bring her belongings to her. Soon other things, such as a bright scarf, a basket or a favorite necklace, found their way to her bed where they would spend a few days as a focal point and then be quietly replaced with something else.
We tried several ideas that kept our mom’s restricted lifestyle as normal as possible. With some adaptation and imagination, perhaps they will work for you:

**DECK THE WALLS.** We gathered family photos, put them in inexpensive frames and hung them on a bedroom wall where my mother-in-law could easily see them. More than 20 photos occupied her “Wall of Fame,” surrounding her with love and serving as a conversation starter for visitors. If you can’t create a photo wall, clip photos to a small tree branch anchored in a coffee can or string a photo clothesline across a corner of the room.

**MAKEOVER MAGIC.** A room makeover can transform a hospital-like atmosphere into a cheerful, homey room. Using low-odor paints and working quickly, we spruced up her bedroom with a new wall color, hung inexpensive new curtains and brought in a comfortable chair from another part of the house. Something as simple as a bright bedspread or new lamp can make an invalid feel proud of where they live.

**BE A PEN PAL.** The disabled are often unable to correspond with friends. Keep a pack of note cards, stamps and a pen handy and offer to write a short thank-you note or letter on their behalf. Sometimes Mom would dictate what she wanted me to write, but often she asked me to compose the note and she signed it.

**SPREAD THE WORD.** Let others know your loved one is lonesome. When a disabled person is out of circulation for a time, people sometimes forget about them or they may be hesitant to visit because they are unsure of the patient’s condition. Invite church members, former co-workers or neighbors to visit and suggest a time that’s best. Let them know what to expect by offering simple guidelines such as, “Before lunch is the best time to call because Mom naps in the afternoon.”

**SHOWER WITH BLESSINGS.** Personal mail provides much-needed contact with the outside world. A few weeks prior to Mom’s 87th birthday we contacted friends and family through phone calls, emails and church bulletins, asking them to mail her a birthday card and, if possible, include a short note or recent photo.

**SHOP ‘TIL YOU DROP.** Mom was unable to handle the complexities of shopping by phone, so we helped her keep some measure of independence by providing gift catalogs. She would browse at her leisure, circle items she wanted to buy and then we handled the actual purchase for her.

It is never easy to see someone you love become isolated because of injury or illness. But with concern and creativity, there are ways to bring the world to them and keep them involved in life — even if it means a few forks in the bed.

Karen Robertson was a caregiver for her mother-in-law.
At Compassus in Leesport, Pa., we try to do as much as we can to make the lives of our patients and their families’ lives just a little better. One way we do this is by asking if there is anything more we can do as we end a visit.

Patient Richard Smith’s answer was simple: he just wanted a cup of coffee. Many people seem unable to find something that makes them happy and are always looking for more. For a hospice patient, however, happiness can be a straightforward matter.

Our team took that request one step further and arranged to transport Mr. Smith and his wife Margie to Cracker Barrel for a special meal and, of course, that cup of coffee. While having brunch with Constance Koch, our director of clinical services, the Smiths shared stories of their lives and 60 years together. It was a special moment for everyone and we were so happy to provide the Smiths this nice date out together.

So what keeps a 60-year marriage strong? Love, laughter, lots of humor and a good cup of coffee.

Katie McNulty is volunteer coordinator for Compassus in Leesport, Pa.
HAPPY ANNIVERSARY
HELPING A PATIENT MARK A RARE MILESTONE

CELEBRATING 71 YEARS OF MARRIAGE

Few couples are lucky enough to celebrate 71 years of marriage. So when Compassus caregivers serving West Plains, Mo., learned hospice patient Mildred Risner and her husband Hubert were preparing to mark this important milestone, they leapt to action.

Together with the staff at West Vue Nursing and Rehabilitation Center, where Mildred is a resident, they organized a surprise reception for the couple on May 3, 2018.

“It was such a special moment to witness,” says Teresa Perkins, bereavement coordinator at Compassus – West Plains. “I am so proud to be a part of an organization that cares so much for its patients and families. This experience is something I will always cherish.”

Mildred and Hubert met in 1947 when she was 18 years old and he was 21. She enjoyed raising rabbits while Hubert worked for the International Shoe Co. and a local hospital for many years. At 92 years old, he continues to raise goats and cut and sell firewood.

When asked the secret to a successful marriage, Hubert answered, “We’ve worked hard our whole lives.” 🌼
Kaiden Ott, affectionately known in the Tullahoma, Tenn., community as “the Heart Hero,” came into our lives on May 15, 2018. Our hearts are always heavy when we bring young children like Kaiden onto our service, but as with all our patients, we feel so honored and privileged to be able to walk this path with them and their families.

In the few months we spent with Kaiden, 4, and his family we shared many great memories that we will keep with us forever.

Soon after his admission, our hospice’s social worker Susan Davis learned the family did not have a family photo. Luckily for us one of our volunteers, Candy Couch, is a photographer by trade and hosted a photo shoot for the family.
With support from various members of his care team, Kaiden was given a mini motorcycle to ride in a communitywide “Ride for Kaiden.”

June 2 was declared “Kaiden Ott Day” in Tullahoma. During the “Ride for Kaiden,” the Tullahoma Fire Department presented the honorary fireman with his very own personalized fire helmet and brought a truckload of superheroes to visit him. We were so grateful for the outpouring of love and support for Kaiden and his family on that special day.

June 25 was a difficult day — it was the day Kaiden passed. A few days later we celebrated this precious boy’s life surrounded by all of those who had supported him throughout his journey, including his firefighter, police and superhero friends. The Tullahoma firefighters served as pallbearers and carried his little casket out to a vintage firetruck, and little did we realize what was to come.

During the funeral processional — a rainy three-mile trip from the funeral home to the cemetery — there was a police officer stopping traffic at every light with their hand over their heart. We passed two fire stations each with firefighters standing outside and hands over their hearts and one with its firetruck out, ladder fully extended with an American flag waving. Along the way there were even locals standing outside of their businesses paying their respects. It was truly one of the most reverent funeral processions I’ve ever been part of.

Life is so fragile, precious, challenging and so very beautiful, and what carries me, this family and so many others through all of this is our faith and the promise that we will see each other again and it will be glorious.

What a beautiful thing to witness the support not only from Kaiden’s amazing family, but from our friends, community and Compassus family.

Julia Logan-Mayes is volunteer coordinator for Compassus in Tullahoma, Tenn.
GONE FISHIN’

By Janet Gard

Like most fishermen, John Patton always loved the feel of a fishing pole in his hand, especially when he felt a tug on the end of the line. So when Ginger Harrison, a volunteer coordinator for Compassus in Branson, Mo., asked the retired Ohio state trooper if he had any wishes to fulfill, he requested wetting a hook one more time.

Table Rock Lake — a fisherman’s paradise — is within a short drive of Wedgewood Gardens, the assisted living center where John lives in Branson West. Table Rock is renowned for its large numbers of white bass, Kentucky spotted bass, crappie, large bluegill and catfish.

Ginger contacted local hospice volunteers Gail and Bill Compton, who arranged for their friends Jim Kanyo and Mike Brandsma from United Methodist Church of Kimberling City to furnish a boat and gear and act as fishing guides.

John, accompanied by nursing aide Lee Richardson, boarded the pontoon boat, cast his line and spent a good day swapping tales with his new fishing buddies while waiting for the fish to bite.

We cherish the special memories we create with our patients and are thankful to Wedgewood Gardens and United Methodist Church of Kimberling City for helping us to create this meaningful moment for John.

Janet Gard is executive director of Compassus in Branson, Mo.
BY THE NUMBERS

There’s no place like home

64%
About 64% of Medicare hospice patients were 80 years of age or older in 2016.

44.6%
Nearly half of the 1.04 million Medicare beneficiaries who died while in hospice care in 2016 were in their own homes.

55.6%
In 2016, most days of care were provided at a private residence.

13
After a patient’s death, Compassus offers bereavement support to grieving families for 13 months.

24/7
Hospice care is available “on-call” after the administrative office has closed, seven days a week, 24 hours a day.

94%
About 94% of families who had a loved one cared for by hospice rated the care as very good to excellent.

1.65 million
Hospice cares for more than 1.65 million Americans and their families every year.

88%
A Gallup poll reveals that close to nine in 10 adults would prefer to die in their homes, free of pain, surrounded by family and loved ones.

24
The median length of service for Medicare patients enrolled in hospice in 2016 was 24 days.

Source: National Hospice and Palliative Care Organization
Attending funeral services for my old friend Waymon Watkins in McComb afforded the opportunity to see a lot of people I’ve missed for the past few years, as well as evoking memories of bygone days in the town where I spent most of my newspaper career.

As people grow older they naturally are drawn to more memorial services, either in person or in spirit, and I certainly qualify as one who has attended and been a pallbearer at my share.

But no one I know has participated in more funerals than Dr. David Millican, who, along with Rev. Jeff Van, conducted Waymon’s funeral. Also participating were Philip Alford, who sang a medley including two of my favorite hymns, Beulah Land and Amazing Grace. Waymon’s daughter Lucia Holland delivered a moving eulogy spiced with humor that Waymon would have appreciated.

Millican and I moved to McComb about the same time in July 1963. He was at South McComb Baptist Church from that year until 1996, when he retired as pastor and became the chaplain at Southwest Mississippi Regional Medical Center as well as being an interim pastor at a number of churches.

Presently, he is with Compassus and ministers to folks in their last days, as well as preaching or
speaking at funerals.

He told me in a telephone conversation that he has spoken at 2,192 funerals so far during his ministry.

I doubt anyone in McComb’s history matches that record, unless it was the late Dr. Wyatt Hunter, who served as pastor of McComb’s First Baptist Church for 30 years before retiring to become the church’s pastor emeritus and also serving in interim roles.

Millican says he has been asked if attending so many funerals becomes depressing. Not so, he responds. You meet a lot of good people at funerals and you renew old acquaintances, as I did last week.

Of course, seeing loved ones depart is sad for families and friends, and when a young person dies it can be heart-wrenching. But when the deceased has lived a long, fruitful life and is suffering from the ravages of age and disease, the memorial can be a celebration.

Reflecting on Millican’s career, I am reminded of the influence a person like him can have on not only his own congregation but those throughout the community. Sometimes even gentle pastors can be intimidating.

A story that sticks out in my mind occurred around 1970 or a couple of years later. Drive-in movie theaters were beginning to fade away, but one was continuing to operate in South McComb.

It was staying afloat by featuring X-rated movies, some no more sexually explicit than what you can see now on your television set at home.

But at that time a lot of folks in McComb were not as tolerant of such as the general public is today.

One of my duties was to cover the McComb City Board. One night during a regular meeting the board room was full of people there to ask the city to take action to ban those X-rated movies.

Dr. Millican was there, along with a lot of his church members. I noticed near the front was an employee of the Enterprise-Journal whose job was to catch newspapers as they came off the press and help get them ready for distribution.

He was something of a character who wasn’t bashful about voicing his opinions, especially when teased by people like me.

As I was writing my City Board report the next morning, this guy came into the small newsroom we had in the old E-J building on North Broadway and asked me what the board decided.

“They are going to contact the owners of the drive-in theater and ask them to stop showing X-rated movies,” I told him. “If that doesn’t work, they’ll probably take other action.”

He went into a tirade, implying that they were violating his right to watch what he wanted to.

I reminded him he was at the meeting and no one, including him, had defended the movies.

“Why didn’t you speak up?” I asked.

“Well,” he replied, “I wasn’t going to say nothing in front of Brother Millican.”

Reflected with permission by the Enterprise-Journal in McComb, Miss.

Reflecting on Millican’s career, I am reminded of the influence a person like him can have on not only his own congregation but those throughout the community. Sometimes even gentle pastors can be intimidating.
“Would you be willing to help a woman and her 7-year-old child who live farther away than your farthest patient?”

That’s the way my relationship with Laura began about two years ago. Our clinical director called to ask if I would travel 20 miles past my most distant patient to see this new person. I agreed. So one day, when I normally would drive home after seeing my last patient, I turned in the opposite direction to meet a family that would change my life.

I found Laura in the living room, sitting where she could look out the front windows to the peaceful vista beyond. She was smiling as I said hello — I would soon learn that she was always smiling.

Laura was a young 51-year-old with an adult daughter, Kristin, and a lively, loving 7-year-old daughter, Maggie. It was clear from the outset that Laura had a degenerative brain illness that mimicked Parkinson’s disease. She was having difficulty getting around and she fell often, but she didn’t want to use a hospital bed or a walker because she was worried about what it would mean to Maggie. A special beach wheelchair allowed her daughter, Maggie, to take Laura to the water’s edge where she could wiggle her toes in the ocean.

By Robin Bugbee
I met with Laura twice a month for two years. She always was smiling, and I never heard her complain about anything. She was determined to be there for her two daughters just as long as she could, and to actively participate in their lives.

Laura and I shared a strong Christian faith, so I read her scripture and Bible passages and sang her old hymns I thought would lift her spirits. But to tell the truth, her spirits were usually already lifted. Frequently, it was my spirits that needed help and restoration, and a trip to Laura’s house always helped.

Laura was a wonderful loving woman who understood that, despite her illness and the pain and sadness it brought her family, her life — all of it — had been a magnificent gift of love from God.

At the end of her last summer, a kind of miracle happened. We were alone one beautiful day, and I asked her a question I had been putting off because of the finality it supposed: “Is there anything you would really like to do that you have not been able to?”

Her first choice — to go skydiving — was impossible because of her failing health. Laura then said, “It would be wonderful if we could make one more trip to the beach so Maggie and I could put our feet in the water and wiggle them around.”

One day a few weeks later, Laura’s niece drove Laura and Maggie down to Sullivan’s Island, where I met them with a beach wheelchair with big balloon tires. Maggie pushed her mother in that chair to the water’s edge where they both sat on a sunny, just-about-perfect day and wiggled their feet in the cool ocean water. It was a magnificent day, with lots of smiles all around.

Despite the sadness she had experienced, Laura was able to embrace the good with the bad. If we are fortunate, we can, with God’s help, reconcile the people we are with the people we would like to be and come closer to living the life God wants us to live.

It is our great gift to help each other reach that. Laura understood it, and as I sometimes struggled to take care of her, she, with the grace of God, took care of me — always concerned about my life and how I was dealing with my responsibilities.

Sadly, Laura’s health began to fail around Christmas and she died in the local hospital right after the first of the year.

I will always be thankful for the gift of love she so freely gave to her family and everyone she knew. Through this wonderful work of pastoral care, I will continue to share that gift with as many others as I can.

Robin Bugbee is a former chaplain for Compassus in Charleston, S.C.

Laura and Robin Bugbee shared their strong Christian faith with each other.
Debunking the Myths of Hospice

By Naomi Naierman and Johanna Turner

Hospice is a set of services that we all may need some day — if not for ourselves, for our parents. While death is not a chosen option for any of us, we do have choices about the services we use at the end of life. Hospice is undoubtedly the best option in the last months of life because it offers a whole variety of benefits, not only to those of us who are dying, but also to those left behind. Yet, despite its many advantages, hospice is still a mystery to most Americans, decades after its introduction to this country.

To learn about hospice, it is useful to start with debunking the common myths that, in themselves, create barriers to hospice.

**MYTH:** Hospice is only for people who can accept death.

**FACT:** While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences.

**MYTH:** Hospice is only for dying people.

**FACT:** As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Most hospices make their grief services available to the community at large, serving schools, churches and the workplace.

**MYTH:** Hospice is a place.

**FACT:** Hospice care takes place wherever the need exists — usually the patient’s home. About 70 percent of hospice care takes place where the patient lives.

**MYTH:** Hospice care is expensive.

**FACT:** Most people who use hospice are over 65 and are entitled to the Medicare Hospice Benefit. This benefit covers virtually all hospice services and requires little, if any, out-of-pocket costs. This means that there are no financial burdens incurred by the family, in sharp contrast to the huge financial expenses at the end of life which may be incurred when hospice is not used.

**MYTH:** Hospice is only for people who can accept death.

**FACT:** While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences.
MYTH: Hospice is only for old people.

FACT: Although most hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care.

MYTH: Hospice is for people who don’t need a high level of care.

FACT: Hospice is serious medicine. Most hospices are Medicare-certified, requiring that they employ experienced medical and nursing personnel with skills in symptom control. Hospices offer state-of-the-art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

MYTH: Hospice is only for people with cancer.

FACT: More than one-half of hospice patients nationwide have diagnoses other than cancer. Hospices also serve families coping with the end stages of chronic diseases, such as emphysema, Alzheimer’s, cardiovascular and neuromuscular diseases.

MYTH: Hospice can only help when family members are available to provide care.

FACT: Recognizing that terminally ill people may live alone, or with family members unable to provide care, many hospices coordinate community resources to make home care possible. Or they help to find an alternative location where the patient can safely receive care.

MYTH: Hospice is for when there is no hope.

FACT: When death is in sight, there are two options: submit without hope or live life as fully as ever until the end. The gift of hospice is its capacity to help families see how much can be shared at the end of life through personal and spiritual connections often left behind. It is no wonder that many family members can look back upon their hospice experience with gratitude, and with the knowledge that everything possible was done toward a peaceful death.

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EXPLAINING HOSPICE TO A YOUNG CHILD

A few years ago one of my patients had a young grandson, and I wasn’t sure the boy understood what hospice was really all about. I got to thinking that most young children probably don’t comprehend the complexity of hospice, so I wrote this poem to try to simplify it. It’s written from the perspective of a grandfather talking to his grandson.

What’s it mean you’re on hospice — inquired the young lad
does that mean you’re going to die and leave us feeling sad
does it mean you won’t be around — watching me playin’ ball
or give me hugs and kisses — when maybe I take a fall.

I don’t think I like hospice Grandpa if they’re going to let you die
why don’t they get you well Grandpa — then maybe I wouldn’t cry
it doesn’t seem right — I don’t want to let you go
You’ve always been my hero — you know, I love you so
it’s alright Tommy I understand the way you feel
see — God has a plan for me — this is just part of the deal
hospice is a gift Tommy — God has given them this chore
they are here to help me, like angels walking through my door

God has called me to come to Heaven — my time on earth is done
he could have chosen others — but he said, ‘you’re gonna be the one’
God needs me there in Heaven Tommy — to help little kids like you
teach them as I’ve taught you and help to pull them through

show them how to respect their elders and treat everyone the same
let them know it’s okay to lose — remember, it’s just a game
to always be thankful for your character — it means more than you now know
remain honest — cherish your values — admit your mistakes and grow

remember wealth is not measured in the money that you possess
practice generosity — giving is honorable — receiving means much less
‘yes’ — it’s better to give than to receive — I hope I’ve taught you this
don’t hold a grudge against anyone — especially your little sis

trust others but forgive quickly — discipline is such a virtue
it’s okay to disagree — doing it humbly though best serves you
be a good friend — learn from others — be content with little
respect others’ feelings — remember — never to belittle

choose the path less trodden — select the one that narrows
don’t always be a follower — sometimes you must take the arrows
be open for criticism but make sure to have an opinion
be able to accept change — appreciate the life you were given

be thankful for your parents — they’re trying to help you learn
overcoming your difficulties and frailties is only their concern
put things that matter most in your life at the very top of your list
make a change in the world — try not just to exist

live your life to the fullest Tommy — you’ve only got one life to face
remember to put God first in your life — things will fall into place
always let patience be your first response and kindness your first reply
may faith be your first inclination — never be afraid to ask why

these are some of the things Tommy that God has asked me to do
to be a messenger of his love and devotion — for children just like you
to accept the hospice people — they are just a part of his team
to make my transition seem peaceful — somewhat like a dream

so when the day comes and I go off to a final sleep
try hard not to be sad my grandson and try hard not to weep
let’s say our goodbyes now — we’ll meet again some day
this is all just part of God’s plan — he will show us the way. 😊

Gary Blackmore is a volunteer with Compassus in Columbia, Mo.
Everyday Compassion
Vol. 9 Issue 2

STRUGGLING WITH GUILT
RESCUING YOURSELF FROM THE SHOULD’VES AND COULD’VES

GRAHAM’S “6/4 RULE” for the grieving

By Graham Paterson

After a loved one passes, surviving family and friends may criticize themselves — sometimes mercilessly — over something they believe they could, or should, have done better.

It is in these situations my “6/4 Rule” seems most helpful.

My 6/4 Rule is simply this: the relationship of two sets of words. The first set is six words: “I did the best I could.” The second set is four words: “Be kind to ______” (insert name of the person criticizing himself or herself).

So often, grieving people are very kind to others yet forget to be kind to themselves. The primary way to be kind is to remind yourself you did the best you could at the time. It is now time to be kind to yourself.

My wife Anna recently lost her father after he had been in hospice care for more than a year and a half. After Anna’s sisters shared details of her father’s deteriorating health, I realized his death was reasonably imminent and helped prepare Anna, as I thought he would not live through the week.

We came up with a plan for a conference call between Anna, her ailing father, her nine siblings and Anna’s daughter Sarah. The call was scheduled.

Unfortunately, Anna and I were in the mountains of New Mexico when the call occurred and the phone reception was terrible. Then the battery on Anna’s phone died and she missed the call.

Anna’s siblings and Sarah got to talk with her father, and he with them. Anna was deeply disappointed she missed that experience, but she planned to call him the next day.

To her great distress, Anna’s father passed during the night, as she learned from a 4:30 a.m. call.

The news distressed Anna greatly. “I didn’t give him permission to die!” she called out. “I needed to speak to him first!” She was inconsolable.

After several hours, I asked her if she had ever heard my 6/4 Rule of grieving. She said no. I reminded her she had done the best she could at the time and had she not shared the idea of the conference call, her siblings undoubtedly would have regretted not having spoken with their father before he passed. I reminded her that her daughter had been on the call and represented her well. I also then reminded Anna to be kind to herself.

In the midst of grief and loss, the 6/4 Rule is a powerful reminder to show yourself the same kindness you would extend to others.

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In the midst of grief and loss, the 6/4 Rule is a powerful reminder to show yourself the same kindness you would extend to others.

Graham Paterson is chaplain for Compassus in Round Rock, Texas.
Believe in a Better Today and Trust in a Better Tomorrow

By Monica Perez

He never said life would be a bed of roses
But said, come to Me all that are burdened and heavy laden
And I will give you rest
Believe in a better today and trust in a better tomorrow

When life seems to change before you
And fear seems to grip you
Cling to the One who understands your every need, question and heart’s cry
Believe in a better today and trust in a better tomorrow

When life is all as it should be
No struggles or challenges do you face
Don’t let your guard down; continue to run the race
Believe in a better today and trust in a better tomorrow

When you have all you need
And life feels great indeed
Never forget your friends and family He has blessed you with to see
Believe in a better today and trust in a better tomorrow

When you go about your day, appreciate all you have
Never take for granted
The ability to feel, touch, and see all of life’s pleasures

It may be a sunset or sunrise
It may be a look in your loved one’s eyes
It may be the smell of a fresh-cut lawn
Or flowers picked and delivered from your grandbaby’s little hands
It may be a smile or hug given to someone just because

Whatever life’s simple pleasures are for you
Pause, stop, ponder and listen
Give thanks to our Father in that moment
Take time to embrace the beauty around you

Live, love and laugh through this journey we’re on together
Know you’re not alone, for He is right there with you
Always believe in a better today while trusting in a better tomorrow

Monica Perez, a former certified nursing assistant for Compassus in Yuma, Ariz., writes poems based on her life experiences.
When Danelle Dunaway became a hospice volunteer a little more than a year ago, she met Elaine Blanco, the very first hospice patient with whom she would be assigned. It didn’t take long for these two to create a bond that makes them feel more like family than patient-volunteer.

“She has gotten very close to Mrs. Elaine and pretty much considers her like a grandmother,” says Tanya Curry, volunteer coordinator for Compassus in McComb, Miss.

Elaine resides at Billdora Senior Care in nearby Tylertown, Miss., and Danelle visits her there every single week, including holidays, Curry says.

“Danelle actually went and visited Mrs. Elaine on Christmas afternoon to take her a gift,” she says.

Elaine is “a sassy little lady who keeps me on my toes,” Danelle says, with a smile.

And though she receives accolades for volunteering her time to hospice, Danelle shrugs off any praise.

“Volunteering for Compassus has been one of the greatest blessings of my life,” she says, “and it is truly an honor.”

Volunteer Danelle Dunaway celebrated Elaine Blanco’s birthday with a beautiful bouquet of flowers.
THE BOOKSHELF
RESOURCES THAT FAMILIES MAY FIND HELPFUL IN THEIR HOSPICE JOURNEY

Comfort and care among the pages

As you face the end of life — your own or someone you love — and search for understanding, the experience and knowledge of others can help.

These books, recommended by Kurt Merkelz, Compassus senior vice president and chief medical officer, and Synthia Cathcart, Compassus vice president for Clinical Education and Development, are among the most beneficial.

THE 36-HOUR DAY
By Nancy Mace

Whether a person has Alzheimer’s or another form of dementia, The 36-Hour Day will help family members and caregivers address the challenges while coping with their own needs.

This updated edition includes new information on devices to make life simpler and safer for people with dementia; strategies for delaying behavioral and neuropsychiatric symptoms; palliative care, hospice care, durable power of attorney and guardianship; and support groups for caregivers, friends and family members.

The central theme: much can be done to improve the lives of people with dementia and of those caring for them.

ON GRIEF & GRIEVING
By David Kessler and Elisabeth Kübler-Ross

Elisabeth Kübler-Ross’s 1969 groundbreaking On Death and Dying changed the way we talk about end of life. Now On Grief and Grieving, co-written with Kessler, one of the world’s foremost experts on death and grief, influences the way we experience grief.

The book applies Kübler-Ross’s five stages of death — denial, anger, bargaining, depression and acceptance — to the process of grieving, with sections on sadness, dreams, coping, children, healing and isolation.

“I now know that the purpose of my life is more than these stages,” Kübler-Ross says. “It is not just about the life lost but also the life lived.”

BEING MORTAL
By Atul Gawande

Modern medicine has succeeded in making disease, injury and childbirth less deadly and more manageable than in years past. But regarding aging and death, modern medicine runs contrary to what it should. Atul Gawande, a practicing surgeon, offers research and stories to reveal the ensuing suffering.

Nursing homes, devoted above all to safety, battle with residents over food and other choices. Doctors, uncomfortable discussing death, resort to false hopes and treatments that actually shorten lives.

Being Mortal shows how the ultimate goal is not a good death but a good life — all the way to the very end.
Hospice Palliative Care Consultation Program Home Health Premier Care Executive Office

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