The Journey Home
Stories of Compassion and Inspiration
from AseraCare Hospice

By K.T. Anders and John Ross
Dedicated to the AseraCare Hospice staff who give of themselves daily to patients and loved ones, and to K.T. Anders, our gifted and courageous writer, whose presence and memory are interwoven in every word of this book.

AseraCare Hospice is one of the nation’s premier providers of hospice and palliative care services. We treat each of our patient’s end-of-life journey with respect, kindness, compassion and support.

Our family-centered approach works to ensure that the needs and wishes of both our patients and their family members are met throughout the hospice experience. We provide a wide range of hospice care services that include physician, nursing, therapy, social work, counseling, personal and spiritual care.

For more information, visit www.AseraCare.com.

www.aseracare.com

© 2011 AseraCare Hospice

This book is based on real experiences. Some names have been changed to protect the privacy rights of those involved.

AseraCare Hospice welcomes all persons in need of its services and does not discriminate on the basis of age, disability, race, color, national origin, ancestry, religion, gender, sexual orientation, source of payment, or their ability to pay. Medicare hospice services are available on a physician’s certification that the patient is terminal and has a life expectancy of less than six months, and the patient agrees to cease active treatment for conditions related to the terminal diagnosis. AHS-06236-10.

All photography used in this book is from the Thinkstockphotos.com collection.
CONTENTS

Introduction by James Avery, MD ................................................................. 5
Foreword by K.T. Anders ............................................................................ 7

PART ONE
What Is Hospice? ...................................................................................... 10
The Decision ......................................................................................... 13
Overcoming the Fear ........................................................................... 23
Tips from AseraCare on Starting the Hospice Conversation ................. 25

PART TWO
The Hospice Care Team ........................................................................ 26
The Patient’s Attending Physician ......................................................... 27
The Hospice Medical Director ............................................................... 28
The Registered Nurse ......................................................................... 32
The Home Health Aide ........................................................................ 39
The Social Worker ............................................................................. 43
The Spiritual Care Coordinator ............................................................ 48
Volunteers .......................................................................................... 52
The Bereavement Coordinator .............................................................. 56
Making a Wish Come True .................................................................. 60
Hospice Stories .................................................................................. 61

PART THREE
The Journey of the Last Days ............................................................... 64
Tips from AseraCare on How to Help Your Loved One Let Go ............ 72

PART FOUR
Bereavement: Healing, Grief and Support ............................................. 74
Symptoms of Grief ............................................................................. 77
Focus on the Future ........................................................................... 79
Hospice: Your Companion in Bereavement and Grief ......................... 80
Beyond Bereavement ......................................................................... 82

PART FIVE
Families Say ‘Thank You’ .................................................................... 86
**REVIEWS**

“The Journey Home, Stories of Compassion and Inspiration from AseraCare Hospice provides the reader with a unique look at the many benefits patients and families receive when they choose hospice care. Using a wide range of patient stories, this book walks the reader through the stages of struggle and acceptance that many hospice patients experience. While the dying process can be difficult, this book demonstrates how hospice makes the path more comfortable, less lonely and often a triumph for the patient and their family. It is a true example of how medical, social and spiritual expertise can make a person’s closing chapter a tribute to a life well lived.”

J. Donald Schumacher, PsyD  
*President and CEO*  
*National Hospice and Palliative Care Organization, National Hospice Foundation, Foundation for Hospice in Sub-Saharan Africa, Alliance for Care at the End of Life*

“Most people with a family member or friend in their final stage of life know the confusion, fear and anxiety that come during this difficult time. In *The Journey Home, Stories of Compassion and Inspiration from AseraCare Hospice*, readers receive a clear understanding of the advantages of hospice care and gain valuable insight from the men and women that work and reside in a hospice setting every day. Anders superbly captures their struggles, joys and daily triumphs to demonstrate how hospice care meets the needs of both the patient, family member or friend. Ultimately, readers are taken on unique spiritual, social and mental journeys that bring hope, comfort and a peace that passes all understanding.”

Bruce Yarwood  
*President and CEO*  
*American Health Care Association*

“The Journey Home, Stories of Compassion and Inspiration from AseraCare Hospice expertly weaves together instruction on the purpose, structure and services of hospice with a rare and poignant view into the world of those for whom hospice was created — terminally ill individuals and their loved ones. This book conveys the unique and hallowed role that hospice plays in a growing number of lives, and affirms that hospice is a very special way of meeting the needs of Americans nearing the end of life.”

Val J. Halamandaris  
*President*  
*National Association for Home Care & Hospice and*  
*Director-General, World Homecare and Hospice Association*
INTRODUCTION

Medical training rarely deals with stories about the dying. In fact, as a physician I was uncomfortable with the entire subject of death for many years. But once I had mastered the larger intricacies of the “science of medicine,” something mystical — perhaps obscure or shadowy are better words — began to grow in me as I began applying myself to the “art of medicine.” I began to see each of my patients as a unique and sacred story — as a fellow journeyer on the road of life.

No longer was a patient simply a “lung cancer” or a “stroke victim” — a living example of a chapter in a medical textbook. No, now they became people who were good and kind, sons and daughters, lovers and warriors, humble and proud, mothers and fathers, virtuous and not, emotional and stoic — and my work as a physician developed a more human and sacred dimension.

Somehow I have always thought of life as a stagecoach ride; someone else is driving, and I am just a passenger sitting in the back. Occasionally, another person jumps in and we both share that part of the journey together. And that is how I began to view my patients — as fellow travelers through the bumpy and unpredictable adventure we call life. But a shared journey in the world of hospice was unique and special because we both knew this could be the last one.

Could they come to grips with their disease? How would they face their own mortality? How could I help them on this journey? Could I help them find some peace, love, gratitude, forgiveness and acceptance?

In this book, you will get the chance to jump into the stagecoach of another person as you read the tender and poignant stories of people on their final journey. Listen carefully — because every person has something special and sacred to share with you.

As each story ends and you get out of the stagecoach, you will be left with memories that will entertain, inspire and educate. And don’t forget — this is not Hollywood. These stories are true — written by the caring hospice nurses and staff who do the sacred work of AseraCare Hospice.

James A. Avery, MD, FACP, FCCP, FAAHPM, CMD

Chief Medical Officer, Golden Living
I first learned of hospice when my mother was dying of metastasized breast cancer. I went to live with her and care for her until the end. I had no idea how difficult it would be.

Under the best of circumstances, my mother and I had a complicated relationship. We reached new heights of stress as I tried to care for her through her increasing veil of pain and frailty. I felt isolated and alone and spent sleepless nights crying into my pillow. She was filled with anger and fear. We ground against each other at a time when we most wanted to be gentle. Her imminent death was shredding our memories of happier times.

When I finally admitted to myself that I was not helping my mother, and was even making her last days more miserable, I had to turn somewhere for help.

I found the answer in hospice, a program of care and support services for terminally ill patients and their families. My experience with hospice was nothing short of a gift, both physically and emotionally, for both my mother and myself.

The hospice nurse and aides were able to take over bathing and managing my mother’s physical needs. Working with my mother’s doctor, hospice was able to alter her medication to relieve much of her pain, and the nurse even taught me how to administer a shot if my mother was hurting too much.

And when I was in tears, unable to function, the hospice counselor, experienced in

“It’s not easy to lose a loved one. Hospice helped me through one of the most difficult periods of my life.”
the terrible void death brings to the survivors, listened and talked to me. She understood how I felt and had words of comfort and advice on ways for me to cope. My mother and I settled into a quiet time of communication, sharing memories and savoring our last weeks together.

It’s not easy to lose a loved one. Hospice helped me through one of the most difficult periods of my life. To have professionals who understand the nuances and special stresses of end-of-life care is a blessing. It’s one I shall be eternally grateful for.

Unknown to AseraCare, when I was asked to write this book on hospice I had just completed a year of chemotherapy to treat my stage-four inoperable lung cancer, which had been caused by radiation treatments I had received when I had Hodgkin’s disease in my 20s. Fortunately I have responded and tolerated the chemo very well and am embarking on a new course of radiation. But I know that the disease will catch up with me at some point. It is a great comfort to know that my husband and I can turn to hospice when the time comes. I feel relieved that I will be cared for by loving souls. I know I will not have to suffer needless pain and that my husband will have the support that is so necessary for caregivers.

In these pages you will meet my oncologist, Nicholas Gemma, MD, who is a huge fan of hospice, and many hospice staff members whom I have interviewed. They have beautiful stories to tell. I am honored to share them with you. To preserve confidentiality, I have changed the names of the patients, but the stories of courage, humor and caring are true.

It is reassuring to know that the final stages of life can be completed with dignity and peace, filled with the extraordinary comfort that human beings can bring to one another. I encourage families and anyone facing a terminal illness or whose loved one is nearing the end of life to find the hope of hospice at this most difficult time.

— K.T. Anders (Fall 2009)
In Memoriam

In late November 2009, it was discovered that K.T.’s lung cancer had metastasized to her brain. The tumors distorted her vision and produced severe headaches. She began receiving full-brain radiation treatments and was later admitted to the oncology floor at Winchester (Va.) Medical Center. On the evening of December 12 she suffered a seizure, and despite daily radiation therapy, her health continued to decline.

On the morning of December 16, Dr. Gemma and his medical team which included Barbara, the social services oncology nurse, and the floor RN, stood by K.T.’s bedside. Dr. Gemma held her hand.

“Am I ready for hospice?” K.T. asked, looking up at him.

After a brief summary of her odds of recovering enough to return home, Dr. Gemma answered, “Yes, you are.”

K.T. Anders passed away on Christmas morning.

Our Thanks

K.T. was unable to finish this book, though her special knowledge and talent are present throughout. Her husband, John Ross, picked up the writing where K.T. was forced to stop, in Part Four, Bereavement: Healing, Grief and Support.

We thank John for his help in finishing K.T.’s final written piece.
PART ONE

What would life be without our loved ones — spouses, children, extended family, friends — to share it with? They enrich us, fill us with the joys of life and enfold us in times of sorrow. Sometimes they chafe, and we must find ways to forgive them. Sometimes we are the ones who need forgiveness. But whatever our life path, our loved ones are our companions.

And yet there comes a time when we must understand that part of life is letting go, that those very dear people whom we cherish cannot be with us forever. And for ourselves, too, comes a time when we can no longer hold on to life. For just as life has a beginning, it also has an ending. Whether patients or caregivers, we often feel that we face death alone.

Fortunately, there is a place to turn for help. We have a choice when confronted with the diagnosis of terminal illness. One of the gifts during life is the ability to make decisions for ourselves, to be in control of our lives. Similarly, as death approaches, the ultimate gift is to be able to take control of how our days will end. We can choose to make the passing from life a time of great warmth and support — a time to share, to grow even closer to those who have been important to us, a time when pain is eased and the spirit is nurtured.

We can choose hospice.

What Is Hospice?

Hospice is not a place. It is a medical specialty for terminally ill patients — regardless of their specific disease — that can be delivered in a hospital, a nursing home, a hospice facility, the patient’s home or any other place the patient lives. Hospice is available to people of all ages, including children. The purpose of hospice is to focus on care at the end of a patient’s life. But it is more than that. Hospice is a state of mind. It is a turning away from aggressive medical measures designed to prolong life when those procedures are invasive and no longer pro-
ductive. It is a recognition that the end of life is approaching. When dealing with a terminal disease or situation, it’s easy to get caught up in medical details and forget that a patient also has social and emotional needs. Hospice is a holistic approach that cares for the whole patient — physically, emotionally and spiritually.

The philosophy behind the hospice program is based on the premise that everyone has a right to die with dignity in as much comfort as possible, as alert as possible, and with an opportunity for personal growth and for the healing of personal relationships. Because care is centered on enhancing the quality of life even when the end is in sight, hospice is really all about living.

Doctors and nurses who practice within hospice are trained to focus on the patient, not on the disease. Specially trained for end-of-life care and experts in pain
management, their aim is to create a comfort zone for patients without inducing the drug-related fog that robs patients of their will and senses. Entering hospice doesn’t mean a patient must give up his or her regular doctor; hospice doctors work with the patient’s attending physician to customize care.

Hospice never hastens death, but it eases the journey for both patient and caregivers with an emphasis on quality of life over quantity of life. The hospice team — which includes doctors, nurses, aides, social workers, spiritual and bereavement counselors, and volunteers — all trained in end-of-life care, cradles patients and families in its nurturing embrace. It allows patients to focus not on dying, but on the things they find meaningful in their remaining days. That may mean attending that long-postponed family reunion, finishing a pet project or just talking with friends. It may mean attending to end-of-life tasks, such as creating a medical directive or signing a will. It may mean reminiscing about good times and tough times with a hospice volunteer in a “life review.” At a time of life’s greatest transition, hospice services can bring families closer together.

Caregivers are as much a part of the end-of-life process as patients, and oftentimes their needs and stresses are ignored. Families often find themselves exhausted and emotionally spent as a result of their responsibilities. By providing a support system for caregivers, hospice can bring relief. Volunteers can ease caregiving responsibilities by providing respite care, running errands or simply offering the patient companionship while caregivers take some time for themselves. Aides are available to provide personal care to patients and can even attend to household duties. Hospice even provides those who are left behind with

Choosing hospice does not mean giving up. Some patients live far beyond six months, and miracles do happen.
bereavement counseling and services during that first difficult year when all those birthdays, anniversaries and holidays can seem so empty.

Once a patient enters a hospice program, Medicare covers nearly all of the costs of medications and supplies. Hospice can even provide medical equipment, such as a hospital bed, walker or wheelchair, to allow patients to remain comfortably at home. For families struggling with the costs of medical care, hospice provides its own financial solutions.

The best part is that hospice care is designed to meet each individual patient’s needs. There is no set formula, no agenda. Services are made available, and patients and caregivers can choose as much or as little as they desire.

Choosing hospice does not mean giving up. Some patients live far beyond six months, and miracles do happen. Hospice actually represents hope: it’s a time to find love and forgiveness and reconciliation with the past.

Dignity and peace at the end of life are precious gifts to which everyone is entitled. Hospice is there to ensure that no one passes away alone or uncared-for, and that families are supported and comforted in their grief.

The Decision

Sometimes it’s difficult to know just when to consider hospice care. Medically, the time is right when the doctor indicates that life expectancy is six months or less, and that further treatment will no longer be beneficial and may, in fact, cause unnecessary discomfort. The patient’s attending physician or a hospice medical director must give the order for hospice services.

Some doctors struggle with the idea that suggesting hospice to their patients might destroy hope for a patient, but Dr. Nicholas Gemma, an oncologist with Shenandoah Oncology in Winchester, Va., says he doesn’t see it like that. He thinks of hospice as a switch in tactics and doing what is best for the patient.

Dr. Gemma approaches the hospice discussion frankly, but with compassion. “When I realize that I have no more treatment to offer that will be effective, I tell my patients that there comes a time in most people’s struggle with
malignancy when the treatment literally becomes worse than the disease and the toxicities of further therapy significantly outweigh the benefit,” he explains. “It’s not a matter of giving up or quitting but of recognizing that we are at the point where our ability to impact the disease is negligible and we’re going to disrupt the patient’s quality of life to a much greater extent than we are going to improve their longevity.”

For patients and families, accepting that the time has come for hospice care can be stressful and emotional because it means facing the reality of the end of life. So often we would like to turn away from that reality and deny its existence.

Ginny, who has chosen hospice twice — once for her father, who had leukemia, and once for her husband, who had vascular dementia — knows how important it is to accept reality. “Signing the form for hospice is a reality check — a rude awakening,” she said. “It gives you a chill because you are admitting that this is the end and it’s okay for your loved one to die. I think we live in denial, hoping that the doctor and everyone else is wrong. You hope for a miracle and put off a decision — you say we’re not ready to talk about that now.”

But Ginny never regretted choosing hospice. “We have to be able to let go,” she said. “Both my father and my husband had excellent care, and I would not have liked to see them suffer needlessly.”

Hospice is particularly effective when involved as soon as possible after a life-limiting diagnosis — it should not be regarded as a last-minute deathbed service. One of the saddest comments that hospice teams often hear is, “I wish we had known about hospice earlier.”

“Most people wait too late to call hospice,” said Luraine Nuzzo, executive director of AseraCare in Richmond, Va. “They don’t call until about a week before the patient is near death, instead of admitting him or her early when we can go in and do some really good work with the family and give them support. By the time the family realizes time is running out, they are worn down, in the midst of emotional trauma, and confused about what direction to turn.”
Elizabeth’s Early Call

Elizabeth never regretted calling hospice early. Her husband had renal failure. He didn’t want to go on dialysis because there was no guarantee that it would be effective and he didn’t want to spend his days hooked up to a machine. He told Elizabeth that he wanted to stay at home without any drastic medical measures. He wanted to go peacefully and in his own time.

Elizabeth contacted hospice, and she and her husband met with the social worker, the chaplain and the nurse. “They answered all our questions,” said Elizabeth. “They told us my husband had about three months, but he lived for six months.”

Although her husband initially decided against taking drugs for his pain because he didn’t want to feel “foggy,” he eventually decided that morphine was necessary. “But before I take it,” he told Elizabeth, “we need to sit down and talk.” And they did. “We were together 20 years and we sat and talked for hours about our lives,” said Elizabeth. “Then he said, ‘Now I’m ready.’ I told him I was so grateful that we had the time to do this. I couldn’t have asked for any better.”

Because hospice had been involved early, the staff was able to advise Elizabeth and her husband on everything that needed to be done before he passed away. “He decided about his own funeral arrangements — and he could make those choices because we didn’t wait too long,” said Elizabeth. “The decisions are made and you have time to grieve. Everything was done, right down to the flowers, and he had been a part of it. All I had to do was make a phone call.” At the end you feel comforted because your family member had a say in their own end. It doesn’t make losing them easier, but it helps you to deal with it.

So often life is filled with regrets — “I should have done this” or “I could have done that.” Elizabeth had no such regrets. “I knew I’d done everything in my power to help my husband,” she said. “It’s wonderful to be able to keep your family member at home. Hospice sends a great team backing you up. If you think your loved one would be more comfortable at home, keep them at home.
“It’s wonderful to be able to keep your family member at home. Hospice sends a great team backing you up.”
The burden of medical and personal care doesn’t fall on you. Everyone is there, and everything you need is at your disposal. You’re never without a support system.”

**Getting to Know Mirna**

Choosing hospice early can actually add wonderful memories and change the lives of survivors. Lisa’s 89-year-old mother, Mirna, was diagnosed with cancer. What makes this story exceptional is the care given by and relationship developed between Mirna’s family and the AseraCare Hospice team led by Lori, a certified hospice and palliative care registered nurse, and Mary, a home health aide and certified nursing assistant, who supported Mirna in her last 51 weeks of life.

Lisa knew about hospice care after a close friend experienced the benefits of hospice during the end-of-life stage of her mother. Lisa remembered the impact that the hospice philosophy had on her friend and knew it was time to consider hospice care for her own mother when Mirna chose to stop taking treatments. Lisa then went to their physician, who confirmed that Mirna was eligible for hospice care.

Lori came to Mirna’s home to determine her needs. At that point, Mirna was reluctant to accept hospice care as she felt she could “get along all right.” And, Lisa said, “She probably could have,” but it was important to Lisa, and to the AseraCare team, that they get to know who Mirna was before the disease progressed further.

Mirna’s brief reluctance quickly turned into a desire to see her many hospice friends, including Mary and Lori. In no time, Lisa said, “Mother was asking, ‘When is Mary coming?’ or ‘Where is Lori?’ They became a part of the family.”

“I encourage families to consider hospice care for their loved one as soon as they learn that they are incurable,” said Lisa. “That way, everyone — the loved one and the family — has the opportunity to become friends with the hospice team members. Mother would tell the hospice team things that she wouldn’t tell me such as ‘I’m afraid it’s getting close.’ ”
 Asked to describe hospice in her own words, Lisa said, “Hospice is a nurse who gets to know you and helps with all the medical things you’re going through. The team walks you through concerns or questions, and gets updates from and gives updates to the doctor. Hospice is also the home health aides who come in and do anything for you — cook, give leg rubs, bathe you, even water your flowers. Often they’ll just sit and talk with you. They did anything that Mother wanted. They were trusted friends who gave us a break as caregivers. It would have been tough for me to go to work without the hospice team there. It was a blessing.”

During most of a year, Mirna received hospice care in four locations: in her home, then in Lisa’s home, in a nursing home and, finally, at an end-of-life
residence. Wherever she went, AseraCare Hospice followed. “Mother received the full benefit of hospice; it went everywhere with her. We never had to change staff. It was always the same people and continuity of care. Wherever she called home, hospice went,” said Lisa. Even on the weekends, somebody was there. It was clear to Mirna’s family that this wasn’t “just a job” for members of her AseraCare Hospice team.

This became evident when Lori and Mary decided to celebrate Mirna’s 90th birthday with a party, complete with balloons, cookies, potato soup and chicken salad. The entire hospice team attended.

Lisa added, “Mother had 90 great years. Up until the last week or two, we were going for walks. It was a beautiful spring.”

The AseraCare Hospice team didn’t stop supporting Mirna’s family after her death. Lisa and the hospice team stayed in regular contact with one another. Lori and Mary, as well as others from the hospice team, attended Mirna’s funeral, and they regularly checked with Lisa to see how she was grieving. Lori even took in Mirna’s schnauzer, Muffin, and sent photos of Muffin in full Christmas-wear to Lisa and her family.

Lisa shared, “The experience has made me not afraid to die. I know that I’m not going to be in pain and suffering.”

The Choice for Sandy

For Sandy, the decision to enter hospice was like a burden lifted from her shoulders. Sandy had decided to forego a third round of radiation and chemotherapy for her lung cancer. Her disease was progressing, the chemo was taking a toll on her body and her mind, and she felt that her life was spinning out of her control. The cancer had begun to define her. It was almost as if the real Sandy had disappeared and all that was left was “Sandy the cancer patient.” Her oncologist’s nurse suggested it might be time for Sandy to think about hospice.

In her 30-year career as a nurse, Sandy had learned how to care for others.
Now it was time to care for herself. She had been a loving wife and an enthusiastic traveling companion to her husband, Ron, for many years. She had always walked to the beat of her own drummer and she wanted to end her life in the same way. Continuing aggressive, debilitating medical care that couldn’t cure her was robbing her of that opportunity.

Ron and Sandy discussed hospice. Although it was difficult for Ron to adjust to the idea of losing Sandy, as a doctor himself he knew that medicine was unable to help his wife. Still, Sandy gave Ron time to adjust to the idea, and then they spoke to Sandy’s doctor. “He almost seemed relieved that we were the ones who brought it up,” she said. “We decided on hospice and never looked back.”

Rather than waiting until the last minute to enter hospice, Sandy made her choice while she and Ron could still enjoy living together. Hospice made it possible for her to stay at home surrounded by the people and things she loved — the furniture her husband had crafted, photos from their travels. The hospice nurse visited her to take care of her medical needs and bring medications. And when Sandy wanted to talk about her fears and worries, she could confide in a visiting counselor. AseraCare delivered a hospital bed to Sandy’s home so that she would be more comfortable, and the nurses helped educate Ron on how to safely care for her. It was a very special time for the two of them.

Hospice enabled Sandy to leave this world peacefully, with Ron by her side in those final moments. She and he were secure in the knowledge that he would be able to carry on.

TLC in the Nursing Home

It was a nurse in his mother’s nursing home who led Mark to hospice. His mother had broken her hip twice and had been in and out of the hospital. Her quality of life was slipping, and the nurse thought it was time for hospice. “We didn’t know anything about hospice,” confessed Mark. “We thought it was the final step when you only had weeks to live. But hospice is for anytime that you are chronically ill and your life is short.” Mark said that he discussed hospice
with his mother, but although she was smart and well educated, she didn’t seem interested in making a decision. So he obtained a doctor’s order. “When she entered hospice she remained in the nursing home, so her physical circumstances didn’t change.”

What changed was her care. Hospice gave that little extra help and became the point of contact for the family. “It was a relationship that we didn’t have before with the other nurses in the nursing home,” said Mark. “The nursing home was wonderful, but they have limited staff, so you don’t get the personal care that you get with hospice. I had no idea of what was involved with hospice or that it was so all-encompassing. Joy, our hospice nurse, was our advocate. When we had questions, we could always call on her. She explained the different stages that Mom was going through, and told us what to expect, what we needed to do, what kind of communication we should have with Mom. I don’t know what we’d have done without her.”

Mark’s mother was in hospice for three years, which is uncommon but not unheard of. Throughout, Joy was a lifeline for Mark and his family. “Joy was there the whole night with us when my mother passed away,” said Mark. “She prepared the body and made my mother look so peaceful.”

Mark and his family were so grateful that they donated a swing to the nursing home dedicated to Joy. “She had done so much for us. She needed a permanent type of recognition,” said Mark.

**Sharon’s Choice**

Sharon was a country girl. Memories of her childhood and young adulthood in the close-knit community where she grew up sustained her as she grew older, raised two children, worked as a charge nurse on a maternity ward, and took care of her husband, a well-respected community leader and school principal.

When the doctor told Sharon that he had done all he could and that he thought she had only several months remaining, she thought about how she wanted to spend those months. Sitting in her beloved country home, an apart-
ment at her daughter's house, she looked around and knew she didn't want to be in a cold hospital room. She wanted to be close to her two daughters and grandson. Sharon’s decision to enter hospice was a choice that reflected her lifestyle and her personality.

Hospice arranged for her to have the medical support necessary to meet her needs. All of her supplies are delivered, so neither Sharon nor her family have to worry about finding what she needs. The nurses bring her medications and aides help her with personal hygiene, relieving her daughters of that responsibility. Remaining in her home allows Sharon to stay close to her friends, who visit often. She is able to continue to be a part of her church community. Sharon has been in hospice for almost two years. “I would not be here if I didn’t have hospice taking care of me,” she says.

It might be the emotional support from hospice that is most precious to Sharon. The hospice social worker, Sara, comes often to chat with her, and Sharon particularly enjoys reminiscing about her youth and the many changes she has seen in the world and in her own life over the years. “We’ve worked a lot with her on life review,” says Sara. “She loves sharing her memories and knowing that someone would remember after she was gone. But we also talk about the choices she’s made throughout her life. She loves to tell me about her husband, who passed away many years ago. Sharing her stories makes her happy.”

One of Sharon’s fondest childhood memories is the visit from a local doctor who came to her home whenever she or one of her siblings was ill. She recalls the comfort of seeing the doctor arrive and knowing that care was on the way. “You know,” she confides, “hospice is really the best thing since the country doctor.”

Sharon is so thankful for the spiritual and emotional support hospice has brought to her and for the opportunity to live out her days wrapped in a cocoon of country comfort and family love that would have been impossible without hospice.
Overcoming the Fear

Sometimes the biggest obstacle to choosing hospice is just plain fear. In the midst of emotional turmoil and without proper knowledge of what hospice is, people are naturally afraid. Medical care, after all, is supposed to make people well. When families hear that doctors will no longer try to cure their loved ones, they imagine that there will be no treatment. They may envision their loved one in great pain with no one who cares. Or they may fear that their loved one will be overmedicated and become unaware. They may even think that hospice is a means of hastening death.

Nothing could be further from the truth. “Many patients say that they are getting more care with hospice than they were before,” says Mahveen Hussain, MD, medical director of AseraCare Hospice in Stockton, Calif., “Hospice patients and their families need to be assured that help is no more than a phone call away, 24 hours a day, seven days a week. Also, the patient’s regular doctor remains an important part of the hospice team, thus ensuring continuity of care.”

Another misconception is that hospice care must be expensive. Again, the opposite is true. Without hospice, individuals with or without insurance are responsible for the costs of prescription drugs and everyday supplies such as diapers, bed pads and bandages. Once a patient enters hospice, Medicare pays for most end-of-life services, including supplies and prescriptions, regardless of the age of the patient or where the services are provided. There is no charge to the patient for nursing services, therapists or even aides who can bathe and dress patients and even take over some household duties. Hospice can actually lower the cost of care.

Sometimes family members themselves are opposed to entering their loved ones into hospice, fearing that their motives might be questioned — that they might be seen as giving up, or worse, trying to relieve themselves of the burden of care. Says Luraine Nuzzo, executive director of AseraCare Hospice in Richmond, Va., “We have found that the patient usually wants hospice but the family is strug-
gling with the idea. We talk to family members about their loved one’s dignity, about letting the patient make choices, and respecting his or her wishes.”

To help family members make the decision, experienced hospice staff can explain the patient’s disease trajectory — what to expect as the disease progresses and what the care needs will be. Because of the stress they are under, families rarely consider what they will do as the disease becomes more acute. They rarely assess in advance whether they have the resources — financially, physically and emotionally — as well as the ability and knowledge to continue care.

But perhaps the most difficult obstacle to entering a hospice program is simply admitting that the end of life is inevitably approaching. Too often people consider hospice as the place where hope is gone. The truth is, hospice is the place where families and patients can turn away from fear and be led to a place of warmth, where life is cherished and made the most of until it can be no more.

“I would like to think in the end that families and patients trust us to do the right thing,” says Luraine. “They let us into their homes and hearts at the time they are the most vulnerable. They trust we will give them respect and the honor to die pain-free in the place that they choose. My team takes that seriously. It’s not up to us to determine someone else’s choices. Everyone wants to leave this earth on their own terms.”
Tips from AseraCare on Starting the Hospice Conversation

• When faced with a diagnosis of a terminal disease, discuss your options for care, including hospice, with your doctor, family member or clergyman.

• Find a quiet time and a place with no distractions to broach the subject.

• Include as many of the family in the conversation as is comfortable for all. Remember that feelings and reactions may be highly emotional, so give everyone time to adjust to the idea.

• Don’t expect a decision immediately, but give everyone the freedom to discuss the topic in the future.

• Hospice can be provided in your home, in a nursing home, in a hospital or in a hospice facility. But regardless of the venue, hospice provides a team of caring professionals who can manage the medical and emotional needs of both the patient and the family.

• Ask for a free hospice consultation so that you understand the services available. Medicare and many insurance plans cover hospice services.
The Hospice Care Team

Remember that scraped knee when you were six or that bully who made you cry in the first grade? You were lucky if you had someone to run home to, someone whom you could rely on to give you a hug and make it all better. As we go through life we all need people on whom we can rely. Whether parents, relatives, spouses or friends, having someone there — someone who cares — makes it possible to get through the tough times.

The hospice care team is there 24/7 for patients and their families to rely on — with physical care, emotional support and every other kind of help that is needed. That kind of support can be powerful medicine. A study commissioned by the National Hospice and Palliative Care Organization, published in the *Journal of Pain and Symptom Management* in September 2004, showed that because they are surrounded by people who care about them, hospice patients, on average, live longer than those with the same diagnosis who do not elect hospice care.

The hospice care team is composed of a doctor, nurses, home health aides, a social worker, a spiritual care coordinator, a bereavement coordinator and volunteers. Members of the care team visit the patient and family as needed, are in
constant contact with one another, and collaborate at weekly meetings to incorporate their own insight and perspective on the needs of both patient and family.

Individuals at the end of their lives require not just physical care; often there is greater need for psychosocial, bereavement or spiritual care. The team helps both patients and families understand the dying process and what to anticipate physically and emotionally. The unknown is often more frightening than reality. Information from the hospice team goes a long way to relieve anxiety at this most stressful time.

**The Patient’s Attending Physician**

The attending physician and the hospice medical director head the hospice care team. The patient’s own doctor is an important member and is usually consulted and included in all decisions. Patients often have close ties to their physicians, and those ties remain throughout the hospice program. The attending physician is the first to certify that the patient is ready for hospice care.

“I’m a huge fan of hospice,” says Dr. Nicholas Gemma, an oncologist with Shenandoah Oncology in Winchester, Va. He encourages his patients to enter hospice when they have opted to end ineffective life-prolonging chemotherapy or radiation. “I talk about hospice as an extension of my office practice — the hospice nurses are my eyes and ears inside the patient’s home, and that improves my ability to make more intelligent decisions. The nurses can anticipate frequent and unpredictable changes in pain control and quality of life far more frequently than we can try to manage with return visits to the office.”

Often Dr. Gemma has the family in mind when recommending hospice. “I suggest hospice when I see that the family or caregiver is really struggling with the uncertainty, unpredictability and inevitability of the disease. Entering hospice gives them structure around the situation at home and the feeling that there is a safety net there. They don’t have to feel they are out at sea without an anchor. I would say half the time I recommend hospice is to ease the burden and facilitate the caregiver.”
The Hospice Medical Director

The collaboration between the primary care doctor and the hospice medical director is a shift in treatment from aggressive care that attacks the disease to palliative care, which means soothing the symptoms of the disease and keeping the patient comfortable without trying to cure. “As medical director, I am an integral part of the care team in which all are equal players in the holistic care of our patients,” says Jennifer Lowe Ellis, MD, medical director for AseraCare Hospice in Clarksville, Tenn. “We address not only our patients’ physical and medical needs, but also their emotional, spiritual and social needs.”

The medical director consults with the attending physician, certifies that the patient qualifies for hospice care and regularly meets with the hospice team. “We call on the expertise of our nurses, CNAs, social workers, chaplains and physicians,” says Dr. Ellis. “It is the beauty of this teamwork that makes hospice work so well.”

The hospice medical director has oversight for the care plan that is developed for the patient, and monitors changes in the patient’s condition and advises as care needs change. Dr. Ellis describes her role:

“Prior to my work in hospice, I felt particularly frustrated when I encountered families struggling with suffering at the end of life — those who were very elderly and chronically ill in hospitals and nursing homes. I realized that at the end of life, pain and suffering (physical, social, mental and emotional) are often magnified when the medical profession attempts to increase the amount of time a person lives rather than focus on the quality of life a person experiences in his or her final months.”

Dr. Ellis found a home as a medical director in hospice because of her interest in physical, social, mental and emotional quality-of-life issues. “We need the opportunity to nurture the values of forgiveness, love, hope and gratitude,” says Dr. Ellis. “The hospice care team works together to explore and address these needs with the patient and also with the caregivers, be they family, loved ones or facility staff.”
“The hospice care team works together to explore and address these needs with the patient and also with the caregivers.”
“It is a privilege for me, when I am able to do so, to make home visits and experience the environment in which the patient lives,” Dr. Ellis adds. “This not only enables me to care better for the patient and family, but also in many cases teaches me valuable and important lessons about the journey of life and death.”

The ability of the hospice medical director to step in and help patients directly can greatly relieve suffering, particularly if the attending physician is unavailable or unwilling to become involved. Carol, a patient care coordinator for AseraCare, tells this story of Dr. Rickson, a medical director who took charge of a patient who desperately needed care.
“Marie’s husband called and said he needed help. I visited and met his wife. She was so thin and malnourished, probably weighed 50 pounds at the most, and she hadn’t been out of bed for three weeks. In order to admit her into hospice, we needed to have a doctor’s order, so I called her doctor. He hadn’t seen her for almost a year and told me he couldn’t sign the order for hospice unless she came into the office for evaluation or we called 911 to have her taken by ambulance to the hospital. Unfortunately, Marie was not physically able to go anywhere; she was too fragile to even turn over in the bed.

“When a patient has no attending physician or the doctor doesn’t want to sign the order, we offer our medical director as the primary physician. Our medical director, Dr. Rickson, gave the order and said she wanted to go to the home and evaluate Marie in person.

“Dr. Rickson spent an hour talking with Marie and her husband about dying, and their feelings, and whether they wanted further treatment and what the options were. They chose hospice care, but the biggest concern was the pain Marie had in her arm. She couldn’t tolerate touch or movement, and Dr. Rickson determined that it might be broken. She not only assessed Marie’s physical pain, but was able to relieve it.

“Because Marie and her husband said they didn’t have a church affiliation, Dr. Rickson talked with them a little bit about religion. She asked their permission to say a prayer, and they were receptive. And she was able to talk with them about what was to come. Not often do you see a doctor show that much empathy and compassion. I was very moved.

“Without hospice, Marie’s husband would have had no choice but to call 911, and it would have been extremely painful and traumatic for Marie to be put into an ambulance.

“Marie was only with us for a few days, but we were able to give her extra TLC and relieve her pain. Her husband was free to be the husband instead of the caretaker. Without Dr. Rickson’s intervention, Marie would have suffered needlessly.”
The Registered Nurse (RN)

The RN is the case manager for the hospice team, directing care of the physical symptoms of the patient as the disease progresses and consulting with the medical director. This includes managing pain, overseeing the procurement of medical equipment, and monitoring and managing medications. The RN also oversees the home health aides, making sure that the patient’s personal care needs are met.

“I manage my patients’ complete care — physical, mental, emotional, family, everything,” says Nellie Kristofsky, an RN for AseraCare in Pittsburgh, Pa. “I don’t see the people I care for as patients; I see them as people who had a life, who raised a family, who had a job, who made a lot of contributions to their community and country.”

Nellie knows that most of the decisions of patients who are in hospice have been taken away from them. “So who am I to take away whatever decision-making ability they have left?” she says. “We are there to help, but in the long run I don’t think we should interfere with their end of life. They should be able to manage their end of life the way they want to as long as they are comfortable and safe.”

The family is very much a part of the process, and Nellie makes sure she talks with the family every time she visits a patient. And sometimes after she’s left the family, they will call her on the phone and she’ll spend another half-hour talking with them. “Families are watching their loved one deteriorate until there’s nothing left of them,” she says. “You listen, you always tell the truth. There is nothing worse than for something to happen and no one has told them or prepared them. People have often asked me how much time a patient has left. Unless the patient was actively dying, I never knew how to answer. So what I say now is, ‘I don’t know. I’m not in charge of that.’ ”

Giving the Gift of Dignity

Sickness robs patients of their dignity. It can be a debilitating experience that makes patients feel even worse than their disease. The kind of loving care the hos-
Palliative care staff provides to patients and their families is exemplified in this story from Erin Shrader, a registered nurse, and executive director of AseraCare Hospice in York, Pa. Erin received a call at 7:30 p.m. one Thursday while she was still in the office.

“That day was particularly challenging, as we were beginning care for five new hospice patients. My staff were very stretched as they accommodated the needs of these new patients and families and continued to balance the dynamic needs of our current census of around 100 patients. I received a phone call from two frantic daughters whose father, Daniel, was dying. They didn’t know what to do and needed help quickly.

“I realized that our entire team was engaged in caring for our patients, and no one was available to help. When I called Daniel’s physician and the struggling daughters, I learned that the patient had declined rapidly and was suddenly unable to perform his own personal care, a task his daughters had never needed to attend to before. They didn’t know how to bathe and dress his fragile body; this was their father, and they were uncomfortable in the role of intimate caregiver. Julie, the older daughter, had worked all day and been up with her father all night the night before. Her exhaustion was evident in her quivering and raspy voice through the phone lines.

“I arrived around 8 p.m. at the quaint and tidy rural home. Julie greeted me in tears. ‘God sent us an angel!’ she exclaimed. That’s when I knew this was going to be a special night with a special family. Julie introduced me to her younger sister, Natalie, and Natalie’s son and daughter, who had come in from New York to help with Daniel’s care.
“They led me down the narrow hallway to a small room at the back of the house where their beloved father and grandfather was staying. Before they opened the door they warned me, ‘Dad can get a little fresh, so just know that he’s really harmless.’ This wasn’t the first time that I had worked with gentlemen described as ‘fresh’ — another indication that this was going to be an interesting night.

“I found Daniel sitting on the edge of his bed, both arms limply slung over his rolling walker. His nasal cannula was only in one nostril. His thick, curly, white hair was badly disheveled, and the room smelled strongly of a failing human body that needed a good cleansing. He was only half dressed — wearing a cloth-zippered jacket over a cotton polo shirt with a white T-shirt underneath. His legs were bare, and on his bottom he wore only boxer shorts.

“On the seat of his rolling walker were clean warm clothes that he just didn’t have the energy to get into. My heart immediately swelled and sank with this vision of a dignified man, reduced to the frailty of his failing heart and lungs that just couldn’t exchange enough oxygen for him to do the simplest task of putting on his own pants, lifting his arms to comb his hair or lifting his soiled shirt over his head.

“I knelt before him to introduce myself. Daniel was nearly blind from macular degeneration, but he told me he could tell I was beautiful from my voice. He told me he was a car salesman and asked me what I drove. When I proudly replied that I drove a Toyota that had great gas mileage, he immediately informed me that I needed a Nissan — they have much better transmissions. I knew I was going to like this man. He was charming, soft-spoken, and even though his eyes were dulled from blindness, they still sparkled. I knew that this quiet man needed to have his dignity restored — it was absolutely the most important thing, and I could do that for him.

“I went to work gathering his deodorant from the bedside table, his hairbrush, toothbrush, and soap and lotion for a bed bath. The whole time that I bathed him in his bed, changed his colostomy bag, put lotion on his back and
feet, and brushed his thick hair, he told me jokes. And they were good ones! After I wiped the tears from my eyes resulting from a long, hard laugh, I noticed that Daniel was laughing too. As he laughed, I observed the tip of his nose turning a dusky pale blue. Even with his nasal cannula in both nostrils delivering four liters per minute of oxygen, he wasn’t getting good perfusion. I asked him if I could help him lie back in bed. I lifted his swollen legs into the bed, tucked an extra pillow under his head and covered him up.

“After calling his attending physician for comfort and sleep medications, his granddaughter headed out to the 24-hour pharmacy. I sat down with Julie and Natalie and told them what I was seeing. Based on how rapidly he had declined, I could only guess that they only had a short amount of time left with him.

“They had known this intuitively. They asked some questions and expressed their agreement with hospice care. I then headed back to Daniel and explained his Medicare hospice benefit and he signed his own consents. Every single paper. Due to his advanced blindness, he couldn’t see where to sign. I guided his hand so that the tip of his pen would be on the signature line, and he painstakingly signed every last form with the elegant signature of a man who took pride in his name on paper and what that commitment meant.

“His granddaughter arrived from the pharmacy and we gave him the medicine. While he rested, letting the medicine ease his struggle to breathe, I sat at the kitchen table and listened to Julie and Natalie tell stories about the ‘good days.’ By midnight his forehead was relaxed, his respirations were down, and he had taken one pillow out from under his head.

“By this time the sky had opened into a torrential thundering rain, which is so common in Pennsylvania in late August. The family insisted that I stay until the storm passed, and offered to make me food, coffee, or provide a bed on the sofa. I thanked them for their hospitality, for the honor of meeting their family and helping to care for their father, and for the gift of seeing the power of a family united. We exchanged hugs and gratitude, and I set out into the dark rain.
“The next day, Daniel died in his own bed, surrounded by his daughters, his son from Maryland, his granddaughter and great-grandson, the hospice nurse and the hospice social worker. Daniel did not speak to anyone after I left that night. The last thing he told me was how grateful he was for his daughters and the relief he experienced. The hospice aide visited earlier in the day and gave him a clean shave and washed every nook and cranny of his tired body. Daniel was restored to the dignity that was so important to him, and his family was able to remember him, in a way that was much more in line with the man that he was.

“I will never forget this night, this man or this family. Daniel and his family are an example of the reason I became a nurse, and why I tirelessly serve hospice and its ideals. We do amazing things in this world, and I am proud to be a part of it.”
An Unusual Celebration

One wonderful aspect of hospice is the ability for nurses to be flexible and to carry out a patient’s wishes. Laurie Dean, an RN from AseraCare in Altoona, Pa., can attest to the fact that nurses have to be prepared for anything.

“John had been a physician before he went into renal failure and decline. Upon leaving the hospital, he wanted to die at home. I was to meet the ambulance in rural Pennsylvania that night and admit him into hospice. The ambulance had kept his meds going during the journey, but left just a tank of oxygen for his hospice needs when it dropped him off.

“I didn’t arrive until around 8 p.m. because I couldn’t find the house. It turns out there was no house — this was land where he and his wife wanted to build a home and now it was where he wanted to pass away. There was a kind of camp shed for equipment storage, but no electricity, no heat, no water.

“The ambulance was gone when I arrived, and John was sitting in a lawn chair, half in and half out of consciousness. About 20 family members were gathered around a huge bonfire. They had hung lanterns and there were pots of chili and marshmallows.

“I have been trained to take care of situations that aren’t normal, so I went ahead and admitted John to hospice by flashlight. He was in pain and wasn’t able to swallow the pills that his wife had for him, so I crushed them and made them into a paste to put under his tongue to make him more comfortable. I used lotions for skin care and freshened him. I put his flannel shirt on him and made him look like himself.

“We found a cot for John, and his wife crawled in next to him. The family and I talked about the dying process. Everyone gathered around, playing guitars
and singing and telling stories. It was a full moon on a beautiful April night. Every star in the sky was brilliant.

“A nephew sang a song he had written about angels who walk among us, and as he sang, John slipped away around 4 a.m. with his wife curled around him. The peace that came over both of them was phenomenal. The camp glowed with love and spirituality. Everyone cried, but they sang more songs after his death. It was a beautiful and amazing night that could never have happened without hospice.”

Dancing into Heaven

Hospice rallies around everyone no matter where they are in the journey. It’s about learning what is important to the patient and how to ease the transition. Even a patient with Alzheimer’s disease can benefit from hospice care.

Angie Hollis, vice president of clinical operations for AseraCare, tells this story.

“Louise was an Alzheimer’s patient. She had been a USO dancer in her youth — her passion in life had been dancing and she still loved swing and big-band. Because she was unmarried, her family had shunned her. She was 92 when she entered hospice. Her nephew was an AIDS patient and had been totally estranged by the entire family except for her. So there were these two people on an exile journey. He took her out of the nursing home and brought her to his home for her final days.

“She was quite comfortable, with no pain. We helped her nephew make a special, sacred place for her in his home. But she wanted and needed to dance. He put in a surround-sound system and we played big-band music. The whole care team would dance with her when they visited, and although she was in bed, her little toes would just start going along with the music. She was able to leave us in the best way possible — she danced into heaven.”

Blessed Relief from Pain

Pain can’t be seen, touched or experienced by the observer, yet it can be
crushing and debilitating to the one who suffers from it. Part of the mission of hospice is to alleviate pain. Cherie, an LPN with AseraCare, recalls how hospice helped Jimmy, a 28-year-old man with cystic fibrosis. “He had been managing his disease in secret for five years,” she says. “He thought there would be no release from the pain.”

When Jimmy entered hospice, his symptoms of cough and intractable secretions from the cystic fibrosis were not responding well to treatment, and he suffered terribly from sleep deprivation and air hunger from his severe coughing spells. “We were able to sedate him enough to control his coughing and manage his pain, and he was able to relax and rest,” says Cherie. “We provided nursing support and physician home visits and emotional support to his mother. Most important, we gave him the confidence that he could die at home with his loved ones with the best palliative care and least obtrusive medical care that we could offer.” Cherie says that on the day he passed away, Jimmy motioned to her that he wanted to sit up. “He pulled me closer and hugged me,” she recalls. “I think it was his way of thanking me and letting go.”

The Home Health Aide

Tender loving care is the specialty of the hospice home health aide or certified nursing assistant (CNA), whether in the home or in a nursing facility. The aide takes care of the patient’s personal care — bathing, hair washing, assistance in feeding, help getting to the chair or walking a short distance. Aides sometimes give back rubs and lotion rubs. They file and polish nails, and generally take care of the little things. Such niceties — the “buff and polish” — can make even the sickest patient feel better. Depending upon need, aides might fix a meal, do laundry, provide light housekeeping, or simply sit and read or just chat.

Doris Fry, a CNA for AseraCare in Green Bay, Wis., recalls visiting Betty, who had Amyotrophic Lateral Sclerosis (ALS) and couldn’t speak. “She communicated on her computer,” says Doris. “She loved it when I would give her a massage. We got to be very close. Every time I would come in, she would smile or put
a note on the computer about how happy she was that I was there. It was a unique friendship.”

Providing such intimate personal care seems to be a calling for hospice home health aides and CNAs. They feel particularly attached to their jobs. “I feel that this is what I am supposed to be doing,” says Doris. “I get such a feeling of gratification. Hospice is so wonderful — and I think people actually live longer because they have hospice.”

Her sentiments are echoed by home health aide Ashley Crowder at AseraCare in Richmond, Ind. “I love my job,” she says. And Ashley’s patients love her too. “I treat them as if they were my own grandparent or mother or father. If it brings a smile to their face, that’s all I need to know. It makes my day 100 percent better to know I actually made someone feel happy.”

She grew particularly fond of Rita, a woman in her 50s who had cancer and other problems. Rita was in a nursing home and didn’t really like anyone around her. When the family is absent, the bond between a patient and hospice aide can fill that empty space with real comfort and warmth. Ashley tells about how she and Rita bonded.

“I sat down and talked with her. So many times in a nursing home setting, nurses and aides don’t have time for a good conversation with patients. So I take the time to sit and chat and form a bond. Rita and I bonded so well that she wouldn’t let anyone touch her besides me.

“Every day I brought her a jug of tea, because she didn’t like water or juice. She loved strawberry ice cream, so I bought a whole bunch of individual cartons and we’d sit and have ice cream and tea together. She loved it because her family wasn’t around to spend time with her. When I was there, I was her family. I came to think of Rita as a second mom."
“She loved my children, aged 5 and 2. I’d bring them in every other week or so, and we’d sit and have ice cream. She loved talking to the children. My 5-year-old was just starting kindergarten, and Rita gave me all sorts of tips to get him prepared for school.

“I couldn’t ask for a better job,” says Ashley. “Knowing that my face might be the last face they see, mine the last voice they hear, or my touch the last they feel, I have to make it as comfortable and as nice as I can for them. Many times I’m holding a patient’s hand when they take their last breath.”

Aides often go above and beyond the call of duty to assist a patient. Suzanne Helms, an RN for AseraCare in Decatur, Ala., tells this story.

“Alvin, an elderly patient, had but one companion in his home — his beloved little pug named Buddy. Alvin’s son and daughter-in-law lived close by and were there for him for emergencies, but Buddy was there all the time and provided emotional support and friendship day in and day out.

“During the first weeks of hospice care, Alvin would tell the home health aides that he used to bathe Buddy every week and how much Buddy disliked those weekly baths. He even shared with the aides that he might have to give Buddy up because he was too weak to bathe him.

“One day, before the aides started Alvin’s bath, one of them turned to the cute little pug. “Buddy,” she said, “will you let us give you a bath?” To their surprise, Buddy bounded into the bathroom and jumped into the tub. So, of course, Buddy got a bath.

“Now the aides bathe Buddy once a week, and that little wrinkly-faced dog is still doing his part as Alvin’s constant companion. I believe that Alvin’s suffering has been greatly decreased by this simple act of kindness. Bathing Buddy is
not in the job description for home health aides, but those two aides have the right idea about doing what’s right for the patient!”

Carmella’s Way of Caring

Hospice aides are special people. Suzanne also tells the story of Carmella, a CNA in a nursing facility, who was caring for a rapidly declining man.

“Bob became more lethargic toward each evening. The family would visit at different times during the day, but couldn’t come in the evenings due to work schedules and other family matters. During the last week of his life, Carmella would sit with Bob for a few minutes every evening, on her own time, just in case he woke up. The family was very appreciative of all her extra effort.

“During the last day of Bob’s life, he was alert only part of the day. The family, notified by the facility’s nurse of his continuing decline, came to visit for a while and then left. I was on call later when the facility nurse notified me that Bob had expired. I asked if the family was in the room and was informed that family was present. I called our spiritual care coordinator and we rushed to the facility, arriving in about 15 minutes.

“When I walked into the room, there was a lady sitting next to the bed holding Bob’s hand. To my surprise it was Carmella. She said the family had gone home about an hour before Bob passed. “I couldn’t bear the thought that he might die with no one there,” said Carmella.

“By the time we arrived, she had repositioned Bob’s body and assured that he was presentable in case his family came back. When the family was notified of his demise, they said that they couldn’t return that evening but would pick his things up in the morning. I informed them that Carmella was here at the time of death, and they were extremely appreciative. I returned to Bob’s room and our spiritual counselor was ministering to Carmella. I held her hand.

“This had been a particularly tough day for Carmella; this was the second patient to expire for whom she was the primary CNA. Even though she had prepared another patient’s body earlier that day and had seen all of her patients, she
never forgot the ongoing gentle acts of kindness, compassion and sympathy. She is a prime example of our hospice mission statement: *We will preserve the dignity of death for our patients and families so that no one will ever die in pain or alone.* Everyone in our office is proud to be on the same team with her.”

**Jen’s Thoughtfulness**

Regular working hours often blur for hospice caregivers. It was Easter Sunday and Jen had been seeing her patients all morning, passing along her cheer and pleasant disposition to all she came in contact with. The last patient she saw was an elderly man, Bennett and his wife, Susan, who had no children or family with whom to celebrate Easter. At midday, Jen finished her schedule and went home to celebrate Easter with her immediate family.

But thoughts of Bennett and Susan alone on Easter dampened her own holiday. So at 8 p.m. when Bennett answered the door, there was Jen with two plates of Easter dinner for Bennett and Susan to share. Bennett was so touched that he gave Jen a big hug and began to cry. “I can’t believe that someone would do something that thoughtful and nice for me and my wife,” he said.

**The Social Worker**

When a loved one is dying, families are stressed emotionally and physically. The hospice social worker is on the team to assess patients’ and families’ psychosocial and practical needs as well as their understanding of the disease and prognosis. In some ways, the hospice social worker functions as a traditional social worker, helping families navigate legal and financial barriers. For example, social workers can assist families in obtaining powers of attorney, do-not-resuscitate orders and advance medical directives. They can guide families through community resources such as Medicaid, Meals on Wheels and any other services available through to a state’s department of social services.

But the hospice social worker’s portfolio goes beyond such traditional services. It is his or her job to evaluate the strength of the family and support system
We will preserve the dignity of death for our patients and families so that no one will ever die in pain or alone.
and how hospice might be able to fill the deficits. “Some people question why they need a social worker — there’s a negative connotation,” says Sara Moody, MSW, medical social worker for AseraCare in Richmond, Va. “But I try to let them know that social work doesn’t just mean helping with finances. It also means emotional support. We’re with the families and patients in a supportive role, providing active listening. We’re someone they can talk with and validate their feelings.”

“We try to keep an eye out on mental health issues, bereavement, and provide crisis intervention,” says Anna Fleck, hospice social worker for AseraCare in Altoona, Pa. “But our involvement depends upon the structure and dynamic of the family as to whether they feel comfortable with us or not. We are there to give them what they need, not what we think they need. We try not to force ourselves on them.”

Often family members and caregivers have conflicting feelings and guilt about their loved ones and the burden of caring for them. The nurse helps them understand the dying process for their loved one, but the social worker is there to help the family and caregivers understand the process for themselves. “We encourage them to talk and express their feelings,” says Anna. “For example, many times a family member will say that he or she just wants it to be over — and then they feel guilty. We’re there to help explore and give them a safe space to talk about those feelings — the pretty and the not-so-pretty — and to let them know they are normal and OK to talk about. When you have a safe space to talk, it is a great relief. When families are in danger of caregiver breakdown — we can help them keep their loved one at home.”

Anna recalls Fred, an elderly widower facing his own death, who had emotional and spiritual regret about the death of his wife a few years earlier. “He felt he made some wrong decisions that caused his wife some physical pain and suffering. He was very tearful about it,” recalls Anna. “We talked about his feeling of guilt and his sorrow. I told him something the minister said at my mother-in-law’s funeral — that once you are in heaven for five minutes, every pain you had
was a million years ago. Fred got an incredible smile on his face and said, ‘Thank you.’ He was able to let go of that conflict and pass away in peace.”

“When you are privileged to make this journey with a patient, you get these glimpses of how you can make things better,” Anna adds. “It’s not always an incredible huge story, it’s often small things that make a difference.”

Often, as patients get to know and feel comfortable with the care team, they like to talk to the social worker about their lives. One of the tools to help patients is called a life review. It allows patients and families to relive happy times, or even times that were not so happy but were defining for them. “There is a real need for people, when facing death, to assign some meaning to their lives,” says Peggy Durkin, former social worker and now regional vice president of hospice services for AseraCare. “They can review and deal with issues over which they have lingering regret or that they need to resolve with family or friends. It helps them gain perspective. At first patients are hesitant to open up, but once we’ve gotten to know each other for a month or two, we become friends and can chat about their past life — children, job, social activities. It kind of puts their life into a story form.”

Often social workers will ask patients if they would like to create a memory book, or a recording to leave behind. For example, Peggy recalls Janis, a woman in her early 20s who was diagnosed with cancer right after giving birth to her first child. She entered hospice when her son was about five months old. “She was sad that her son would never know who she was or what her hopes and dreams were for him,” says Peggy. “So we spent several months making recordings about what she wanted him to know about her childhood and growing up and some of her happy memories. We created a scrapbook that told the story of her anticipating his birth and what her dreams were for his future. It was very comforting for her to be able to leave that behind.”
Peggy was also able to help Janis’s husband, who was facing raising his son without his life partner. “We could talk about his fear and emotional pain,” she says. “He had no one else to confide in.”

Social workers seem to have magical connections to facilitate a patient’s last wish, such as visiting family members in other states or going to a specific place that was meaningful for their family. “We work with the families and utilize our community resources or churches to help sponsor the wish,” says Sara. “At the request of some patients, we’ve been able to track down estranged family members whom they would like to reconcile with, particularly children.”

Sara tells the story of helping a man in a nursing home to have quality time with his son before he passed away. “Billy was in his 40s and had a 13-year-old son,” she recalls. “We arranged with the nursing home for the son to have a sleepover at the nursing home with his father. We got together some things that would be fun, like silly string and games. They had a wonderful evening together. It not only made them both happy, but Billy could feel good that he’d had that time with his son and his son had a wonderful memory after his dad passed away.”

Sometimes the social worker can use her contacts to make things happen for patients and families that might otherwise be impossible. Ronette Bailey was able to help Peggy, a patient with pulmonary fibrosis. “When we admit a patient to hospice, we ask if there are any uncompleted tasks that the patient wishes could be addressed,” says Ronette. “Peggy stated that she had a son in prison, and she knew that soon she would be unable to make the seven-hour drive to visit him that she had been able to do for many years. She didn’t want to die without being able to see her son in the final weeks. One of our nurses mentioned that perhaps we could have her son moved to the prison facility in Nashville, Tenn., nearer to her home. I went to the State Department of Corrections with a letter describing Peggy’s terminal illness and her desire to be nearer to her son. The son was indeed transferred to the Nashville prison, and Peggy was able to visit him six days before she died.”
The Spiritual Care Coordinator

Spiritual care is an important part of end-of-life care, whether the patient and family have a strong traditional religious background or not. When faced with the end of life, it is not uncommon for patients to wonder what comes next, to question what their lives have meant and to worry about unresolved issues. The spiritual care coordinator can help, either by following the patient and family’s own religious practices and prayers or simply by addressing their philosophical feelings and fears about death and dying.

“My job varies from being a liaison between the patient and family and their parish or, on the other end of the spectrum, being there for them to talk to when individuals have never been in a church or have been away from a church and now they are facing death,” says Pastor Ralph Hamer, a spiritual care coordinator for AseraCare in Altoona, Pa. “They are asking the hard questions: ‘What happens after death?’ ‘How do I handle my guilt?’ ‘How do I say goodbye to my family?’ ‘Who will do my funeral?’ We come in to answer those questions.”

Initially people who have no church affiliation or belief may be intimidated by the idea of a spiritual counselor; they resist being “preached to.” But often when families and patients see that the hospice team is ready to meet them wherever they are — without imposing any judgment on them — then they want to talk.

“Once patients and families know it’s not a judgmental situation — that I’m not going to impose any kind of spirituality on them — they feel more comfortable talking to me,” says Gary Griffith, spiritual care coordinator for AseraCare Hospice in Richmond, Va. “I meet people where they are. I never try to replace a
family’s or patient’s minister. I try to work within the community to make sure they are getting visitations and sacraments if they want them.”

For families and patients who don’t want a specific religion, hospice offers a ceremony called the commendation of the dying, a service that commends the person’s spirit to God’s care. “It can be anything from final prayers to a non-religious way to assure them a gift of new life,” says Ralph. “Some families use it in place of last rites. Sometimes it’s more silent prayer or playing hymns. It’s a way for everyone to let go.”

**Healing Families**

Family dynamics are another dimension in which the spiritual care coordinator can bring resolution. Siblings often disagree about what should be done for a parent facing death. Children and parents often have unresolved enmity. The spiritual coordinator can be a bridge that allows everyone to explore their feelings and come to resolution.

Ralph recalls a patient in a nursing home who had been abusive to his children when he was younger. “We tried to contact his children, but they refused to come,” he says. “We asked them to send a photo of his grandchild, but the daughter told us not to contact her again until he died.”

But this man needed to heal. “One of the staff at the nursing home had a daughter who came to spend time with him, drawing pictures, which we put up on the walls,” says Ralph. “He kind of adopted her — it almost made him feel as if he could have a second chance. We find that, who people were in their younger days, by the time we see them, they can no longer be that person. Whole personalities change, and sometimes it’s hard for the family to see that and let go of old emotions.”
Upon occasion, spiritual care coordinators are asked to perform specific religious duties. “We had a patient who wanted to be baptized,” recalls Gary. “We arranged for a priest to come out, but the patient was confused and she wouldn’t let him baptize her. So I performed her baptism in her home.”

Another spiritual care coordinator, Benny tells of how he baptized a man in his own bathtub just hours before he passed away.

“James had indicated to me in my initial spiritual care visit that he and his wife felt at peace with his salvation, but he wanted to be baptized. Knowing that the patient’s condition was fragile and that there was no time to waste, I immediately contacted my supervisor and asked if AseraCare would arrange to have an ambulance transport the gentleman to a local church so that the baptismal ceremony could be held. With no hesitation, the supervisor gave her consent and I made arrangements with both the church and the ambulance provider right away. Nevertheless, the day that we were to hold the baptismal ceremony, James’s condition declined rapidly, and upon my visit to his home it was obvious to me that the trip to the church was out of the question.

“I recall looking into his eyes as I asked him, ‘James, do you still want to be baptized?’ He softly but assuredly replied, ‘Yes, I do, please.’ I looked at some of the male family members standing around me and asked if they could help me carry him to the bathtub. One of the ladies filled the bathtub with warm water. Everyone was so willing to help carry out this man’s last wish.

“We gently placed a sheet under James’s frail body and carried him to the bathtub. As I looked at the tub filled with water, I realized that because I could not let go of the corner of the sheet I was holding onto, I would not have a free hand to untie my shoes. Without hesitation, I lifted my leg over the side of the old-fashioned bathtub, which seemed to be the deepest I’d ever seen, and I plunged my foot, shoe and all, into the water. I held James’s head in my hands and whispered, ‘Are you okay, friend?’
“I’ll never forget his countenance when he replied, ‘I couldn’t be better.’ In a company of 20–30 friends, neighbors and family members, I lowered his head beneath the water and felt an overwhelming sense of peace. As I drew his head up out of the water, he exclaimed with a smile spread across his face, ‘I feel it! I feel it!’

“With his frail wife at his side holding him and drying off his face at the same time, I knew I had been privileged to be a part of such a beautiful moment. Then came tears of joy by nearly everyone who had been privy to the observance of his last wish.

“James was quickly sponged off and laid back in his bed, which had been made with fresh sheets. I stood beside his bed, and just a few hours later I watched him gently fade away from this world into the next. The memory of that night will always be fresh in my heart.”

Sometimes the job of the spiritual care coordinator goes far beyond prayers and comfort. Mazelle Hughes, spiritual/bereavement coordinator with AseraCare in Houston, Tx., tells an extraordinary story.

“When Oliver entered hospice, we had no idea how much we would be able to provide comfort to him and his family in the next week. Oliver was the 60-year-old father of four children. They were a closely knit, loving family.

“Oliver began to receive crisis care during the week. His daughters told me that their younger brother, Jack, was incarcerated in central Texas. They told me that their father would really like to see Jack before he died. I was actually amazed that they referred to their father’s death, because most of the family members were in denial.

“I contacted the Texas Department of Criminal Justice (TDCJ) and requested a visit and the support of the TDCJ chaplain in informing this young man of his father’s condition. I was told I needed a letter from the doctor requesting a visitation from the prisoner, but that the system didn’t usually grant these visits. I told him that the chaplain would try anyway. Oliver’s doctor agreed that the visit
would be really good for the family, and we faxed the consent and request forms.

“Oliver’s wife, Lizzie, told me that when her son walked into the room on Saturday, Oliver, who had been semiconscious for a few days, reached out with both arms and hugged his son, while calling his name and crying. Lizzie particularly appreciated the fact that the officers brought him without handcuffs. They sat in the living room while Jack visited with his father, and then they allowed the family to make breakfast. The officers ate in the living room while Jack ate with his father. She said this was special because Oliver knew that breakfast was Jack’s favorite meal.”

“You just don’t know what that meant to all of us,” said Lizzie. “Hospice just stepped in and helped us; they took over and guided us when we didn’t know what to do! I will always have this picture in my mind of how Oliver hugged Jack and called his name. My husband slipped away early Sunday morning. I believe he had been waiting for Jack!”

“Lizzie asked me to speak at the service for Oliver,” Mazelle said. She was able to tell the story and express how much she appreciated everything we’d done. ‘You must have the touch of God,’ she told me, ‘because when you asked, they got him there within 24 hours!’ Lizzie said that was a memory that would sustain her.”

**Volunteers**

Volunteers are the willing hearts of hospice, giving their time to do little things for patients that no one else does for them. They provide companionship to hospice patients in their homes, assisted living centers or nursing facilities. Patients and families often request volunteer visits and, depending upon what the patient likes, volunteers might read, share stories and memories, play music and games, pray or just listen. Some volunteers have specialties, such as pet therapy dogs; others have massage skills. For many patients, volunteers are a vital human presence when they are feeling their most bleak and vulnerable. A shared laugh, a story, a held hand — these are precious gifts that take away fear and anxiety and bring a smile.
“Volunteers are an integral part of the team,” says Adriana Cuberos, volunteer coordinator for AseraCare in Atlanta, Ga. “We provide ongoing education and training for them. They help us track how the patient is doing through the disease. The patients really appreciate them and often they become quite close friends.”

“We decide with the family and team whether a volunteer can help them,” says Adriana. “If they are not totally aware, the volunteer just maintains a presence — he or she might play soft music or gently squeeze the patient’s hand so they know someone is there with them. It’s a comfort.”

Volunteer coordinators try to match patients with volunteers who share similar interests. “We put people together who will enjoy each other’s company,” says Adriana. “Some patients ask for volunteers to read the Bible or pray. Others want to talk about something fun. It gives a little escape, a little diversion. They might shoot the breeze about a sports game or about their favorite TV programs.”
Lindsay, a volunteer in Georgia, says she brings joy and happiness to her patients in nursing homes. “One lady likes jokes, so I bring my laptop and we look up jokes and riddles online,” she says. “One lady likes chocolate so I bring her chocolates. Another one likes books on tape. The patients appreciate my visits because, although they may see their family, they don’t want to be a burden and talk about their pain. They need a new face to tell their stories to.”

Volunteer Paul Olson visits a gentleman who loves to play trivia. “He wouldn’t be able to do that if he didn’t have a volunteer,” says Paul. For another patient, who passed away, Paul brought special CDs. “Music is a universal language and she loved the big-band sound from the 1940s,” he says. “When I walked into the room she’d smile and sometimes I’d stay for two hours playing music.”

Larry has developed a special rapport with several ladies he visits in a nursing home. “I call my patients my ladies,” he jokes. “They develop a special place in your heart. I love them and really look forward to seeing them each Wednesday. They light up when they see me and that’s the most gratifying thing in the world.”

One of Larry’s ladies was one of the first airline stewardesses. “I bring an atomizer of perfume and give her a squirt on her wrist. She smiles from ear to ear.” Another woman has two daughters and shared with Larry that she really wished she had a son. “I told her she could adopt me, and she thought that was wonderful.”

When Larry discovered one of his ladies was a former music teacher who loved classical music, he brought her a radio. “I put it next to her bed and tuned in National Public Radio because they play classical music from 9 a.m. to 3 p.m.” he says. “I thought it would provide company for her when people aren’t around.”

Volunteers often form strong bonds with their patients. Nicky, a volunteer
for AseraCare in Atlanta, Ga., tells the story of one patient she had grown particularly fond of who was very close to death. “I’m a hugger — I’m Italian,” she explains. “Laverne and I used to sit on the bed and watch television. So when I saw she had lapsed into a coma, I curled up in bed with her and held her hand. I told her what she meant to me.”

Nicky also brings her own special skills to patients. “I’m a clown and I’ve found that when the clown visits, people really open up. I play a kazoo and we sing songs. I do pocket magic. The clown makes people laugh, which is wonderful because depression is so prevalent in nursing homes. One of the ladies asked me to come as the clown because she said it made her feel joyful. When you can help bridge the pain of their leaving their loved ones, that’s what makes us know that what we are doing is valuable. I’m there a brief period of time with these people, but if I can make that time quality time for them, that’s what it’s about.”

Volunteers also bring respite to harried caregivers who often can’t find time for the demands of their own lives. “A lot of people get so involved in caregiving that they tend to lose touch with everything else,” says Adriana. “A volunteer can sit with a patient while the caregiver goes out for a meal or a movie. It gives them a breather to reconnect with themselves. Sometimes caregivers lose their identity because they’ve been so involved in being the caregiver.”

Volunteers all say that they get much more out of their visits than the patients do. “There’s a lot coming back to me,” says Len. “I feel blessed I’m given the opportunity to spend time with them.”

**A Big Hug for the Dog**

Pet therapy can work wonders on the human soul — not to mention the advantage of sensory stimulation and therapeutic touch. Renee Gasch, volunteer coordinator for AseraCare in Bloomington, Minn., tells how much Bill enjoys visits from a cute little dog named Sammy. “Normally Bill doesn’t speak often or clearly, but when Sammy comes to visit, Bill lights up,” she says. “He’ll say how much he loves dogs, or how soft his coat is. He starts reminiscing about pets that
he’s had. With a nonverbal patient, it’s often hard to figure out what will strike a chord. Being able to pet and enjoy the dog has been so positive for Bill’s quality of life. Sometimes the dog draws a crowd of patients and it makes Bill the center of attention, and he enjoys that also.”

**The Bereavement Coordinator**

Hospice services don’t end with the passing of a patient. During times of loss, families and loved ones left behind are particularly vulnerable to a host of emotions and confusing feelings. If the family is having difficulty adjusting to loss, if they are experiencing disrupting behavior or just need someone to talk to, hospice is there to help them cope for up to 13 months after the patient has passed away.

“Sometimes the family seems to be doing very well, but when the death actually occurs, they have a hard time,” says Terrilynn Deavor, bereavement coordinator for AseraCare in Altoona, Pa. Because everyone experiences grief differently, the hospice staff conducts a bereavement risk assessment of the family after
a patient has passed away. “We look at the family’s relationship with their loved one, whether young children are involved, if they are able to care for themselves financially. It’s all about meeting their needs.”

The bereavement coordinator maintains contact with the family through individual counseling, sending cards and letters, or recommending books that might help them. Each family is served according to its unique set of circumstances and needs. Hospice can also connect families to community support groups or grief psychologists.

Some people simply need to talk. Terrilynn tells of a woman who lost her son. “She couldn’t get out of her house, her husband wasn’t supportive. She was very depressed and cried all the time” recalls Terrilynn. “We met every Friday at her house for over 13 months. As our Fridays progressed, she came out of her depression. She calls me her angel and says she has come to the point that she can finally accept it. It really makes my job worthwhile. We still send cards to each other.”

During another one of her visits to a family who had recently lost their son to lymphoma, Terrilynn delivered a special gift.

Nolan was only 22 when he passed away, but his family remembers him as a gentle spirit who always cared more about others than himself.

“He was one of our youngest patients,” recalls Terrilynn. “He always had a positive outlook. He would be an inspiration to anyone.”

One of the AseraCare volunteers used her sewing skills to create a beautiful keepsake bear for Nolan’s family. The stuffed bear was handcrafted from two of Nolan’s favorite pieces of clothing: a yellow LIVESTRONG® T-shirt and a pair of Puma® pants.

Terrilynn tells of delivering the bear to Nolan’s mother and sister shortly after his birthday. “Words cannot express her reaction to the bear,” she says. “She was so appreciative and could not believe that we had made it for her from her son’s clothing.” Nolan loved wearing his yellow LIVESTRONG T-shirt and wrist
An AseraCare Volunteer made this bear from Nolan’s clothing for you to hold as a precious keepsake for many years to come.

May this bear comfort you with joyful memories of your life spent with Nolan. Our thoughts and prayers are with you and your family at this difficult time.

With caring thoughts,

AseraCare Hospice
band. His mother recalls that he even told her to “live strong” after he is gone.

“We talked for nearly two hours, and she told me all about her son’s life,” says Terrilynn. Nolan loved sports and the outdoors. He was going to college for Forestry.

“His mother explained how much he loved college,” says Terrilynn. “He was looking forward to the unit on bears.” Nolan had a fascination with bears but missed the unit by one week because he could no longer attend classes. The bear is extra special to Nolan’s mother for that reason.

Nolan’s family also constructed a special memorial in their yard. The memorial consists of a serene waterfall and pond, surrounded by flowers and grass. This beautiful area brings his mother peace and a way to feel connected with her son.

Special programs help families to honor their loved ones. An example is a candle-lighting ceremony in which family members each light a candle representing something remembered about their loved one. Another is the Wings for Love program, which purchases butterflies to release in a memorial service with the family present. At most nursing homes, hospice offers a monthly or quarterly memorial service for nursing home staff and families.

Grief workshops during the holidays give survivors coping tools and show them how to remember their loved ones and include them in their holidays. Families are urged not to feel pressured by holiday invitations — that it’s all right to accept only the ones they feel comfortable with. The bereavement coordinator might suggest setting a place at the holiday table for the missing loved one or making a memory wreath to hang up.

Although friends are important at this time, it’s helpful to have trained professionals who understand the grieving process and who can listen without judgment. “Often friends tell them everything is going to be okay,” says Terrilynn. “That’s not enough. I educate them on the stages of grief, and listen and let them know it’s normal to have good days and bad days.”

“Grief is something people shove under the rug because our society isn’t
very accepting of grieving people. We help people move through the stages of grief, and we can see them improving. It’s okay to grieve,” Terrilynn adds.

**Making a Wish Come True**

One of the pleasures for hospice staff is to bring smiles to their patients’ faces, whether that means fulfilling a wish for a longed-for treat or making it possible for a last turn around the dance floor. “Hospice is very individualized. We look at every situation and try to find how we can make this the best for each family and person,” says Peggy Durkin. “We can’t change the course of what’s happening, but we can make patients comfortable and give quality to their final days. Our biggest role is finding what we can do for the individual that makes them feel loved and special.”
Hospice Stories

Here are some stories of patients whom hospice was able to make happy as their time drew near.

A Gambling Man

Ross had always loved going to Atlantic City, N.J., to gamble with his brothers. He was very sick, but he wanted to go one more time. It was important to him because he associated it with family and fun. So hospice arranged for a van with a mattress, and Ross’s brothers drove him to Atlantic City, where hospice had arranged for a room for him to use for the day in case he wasn’t feeling well. “They had a wonderful time,” says Peggy Durkin. “He was so grateful to have that chance with his brothers. He died two weeks later, and his brothers said they had never thought they’d be able to share that opportunity with Ross before he died.”

One More from Mickey D’s

Terry lived in an assisted living facility and was declining, no longer able to get around. He confessed to the hospice aide who helped him with bathing that he was really hungry for a Big Mac®. But he was in a hospital bed and had no family and no way to get to the Golden Arches of McDonald’s®. The next day the aide arrived with a Big Mac. She told all the members of the care team to make sure he was supplied with Big Macs any time he wanted. He laughed and laughed.
**Let Me Hear the Music**

Since Richard’s cancer treatment and subsequent ill health, he and his wife, Lila, had not been able to enjoy the jazz concerts at the zoo in Racine, Wis. He told the hospice team how he wished they could go to one more jazz concert together, and poof — the hospice team made it happen. Aide Chad Ramintho met the couple at the zoo to assist Richard into the wheelchair and carefully guide him down the slope to an even spot to enjoy the concert. Richard and Lila were thrilled to be there. After the concert, Chad followed them back to their home and settled them in. Despite Richard’s illness, the couple was able to enjoy one last time together listening to their favorite music.

---

**Getting Behind the Wheel**

Eric was 21 years old with a rare form of blood cancer from which he was not going to recover. His mother told the hospice team that all this child wanted was a driver’s license. That was all he talked about — when he got well, he was going to get his driver’s license. The hospice team found a very kind magistrate who helped him obtain a driver’s ID, and hospice had it delivered to him. Eric died the next day at peace. “That was the greatest gift you could have given him,” his mother said.

Luraine Nuzzo, the hospice nurse, replied, “It wasn’t just for him, it was for you too,” because the truth was that Eric’s mother was greatly comforted in knowing that her child’s wish was granted.
**Bring on the Super Bowl**

Brad had end-stage sickle cell anemia and was dying. The family was very poor. Hospice had provided a hospital bed for his tiny room, which was so small that it couldn’t hold any other furniture. Brad wanted to sit up in the living room, in the solitary chair, to watch the Super Bowl. Hospice brought him a reclining chair, and the family sat around on the floor as they all watched the Super Bowl together. He called the hospice nurse the next day in tears and said it was the best day he’d had in months. “Just for a few hours I got to be like everyone else.”
The Journey of the Last Days

Death is a physical, emotional and spiritual journey into an unknown realm. Because we can’t see the other side, we fear death and the dying process itself. The approaching death of a loved one is a stressful time for everyone, with mixed emotions, anger, regret, guilt and sadness. Hospice can help both the patient and family work through those emotions without judgment — no matter what they are or how they are expressed — and to understand the physical changes that will begin to take place.

Instead of a time of frantic medical interventions intended to bind a person to life, death can be about release and letting go. Hospice staff, who have been with and seen many people pass away, describe it more often as a beautiful experience that can be filled with peace and love. Family members have an opportunity to say goodbye in their individual way, to acknowledge the place their loved one has held in their lives, and to say thank you. Many patients seem to pass more peacefully when family members assure them that they will be able to carry on.

On the physical plane, the journey of the last days is about the body relinquishing the physical processes that were required to sustain life. Intertwined at the same time that the physical processes begin to shut down, a different journey
begins that moves toward another dimension — a dimension unknown and unknowable in our physical world.

This time of transition can be frightening if family members do not know what to expect. But the process is entirely natural and in no way signifies a medical emergency. Hospice staff can help prepare the family for physical changes and explain each step of the way.

The Hospice Presence

The presence of hospice in the final hours of a patient’s life, whether at home, in a hospital or in a nursing facility, depends upon the needs and desires of the patient and family. Some families want support, others wish to be alone, and hospice honors each family’s preference.

Vigil volunteers are sometimes asked by the family to sit at the bedside. “Often times when the patient is close to passing, the family is worn out,” says Terry Skelley, a vigil volunteer for AseraCare Hospice in Pittsburgh, Pa., who sits with critical patients in the mid-to-late evening. “The family has gone the distance with their loved one and they are grateful to have someone sit with them.” Terry plays
CDs and sometimes sings along with them. “If the family or patient likes, as an active Catholic, I will say the rosary with them. Sometimes it’s enough just to be there so the patient is not alone. I’ve seen families who have to make awful decisions in terms of their time and energy and work schedules. So to have someone to be with their loved one means a lot to them.”

If the family is present, Terry often asks them to tell their story. “It’s amazing what comes back,” she says. “They want to share their memories of their mom or dad and it helps them to remember some better times in their lives. Sometimes I’ll say, ‘Why don’t you thank your mom?’ They are so grateful to have that kind of experience.”

Sometimes patients seem to be waiting for permission to pass away, for some final emotional step. Hospice can help. Carol Skare, RN, tells the story of Lonnie, a beautiful lady who found it difficult to let go until one simple act seemed to bring release.

“Lonnie’s family was by her side every day, expecting each day to be her last. On one of those days, the staff sat with the family and told them how honored we were to be allowed to be a part of Lonnie’s life. Her family happily told us that they were so grateful for all the care our staff had given Lonnie and were often comforted knowing that Lonnie was not alone. Lonnie had always been very religious, and hospice staff would frequently read to her from her Bible. Her family said they appreciated this because they knew how important this was to Lonnie.

“One day when her youngest son was visiting her, the social worker and home health aide were present. Her son told them how his mom used to be so careful about her appearance and always wore red lipstick and how, since her dementia, she never wore lipstick any more. The aide thought about how Lonnie must feel about her appearance. She dressed Lonnie in a different gown and her nurse painted her lips red. Shortly after applying the lipstick, Lonnie passed away.

“Of course no one can know if wearing red lipstick again brought Lonnie her release. But the hospice staff felt honored to give that gift to Lonnie in her last
moments and to be given the gift of learning about her past and her story from her family.”

Prayer and spirituality are seldom addressed by the medical profession. Yet many patients experience a deeper sense of spirituality as death approaches. Spirituality differs from codified religion and may be expressed in many forms. Regardless of a person’s religious denomination, the purpose and meaning of life looms as a large question at the end of life. Addressing spirituality during the final days of a patient’s life, according to the wishes and beliefs of the patient, is an important part of hospice services.

Marie tells the story of Naomi, who was close to death in a nursing home. Her family had not been to visit her, but a staff member at the nursing home had been her adopted family over nearly 20 years, and she was a woman of faith. Naomi needed a pastor to pray for her. “John, our spiritual care coordinator, had seen her the day before and returned,” recalls Marie. “He went to Naomi’s bedside and knelt in front of her, holding her hand. I asked the staff members, including the adopted family member, to come and we all made a prayer circle around her bed. John sang to Naomi and prayed for her. She opened her blue eyes and smiled throughout his prayers. John remained in her presence for an hour that night and came back the next day. Naomi was no longer responsive and she died peacefully and beautifully. She and her loved ones needed prayer and presence before her death.”

**Mental, Emotional and Spiritual Process**

Death, just as life, is an individual journey, and no two people travel the exact same path. The process of death may vary, but it is important to remember that it is a process, a time of preparation for entering the next world. Not everyone prepares for the end of life in the same way, but there are certain steps that many seem to have in common. The timing is individual; it involves how a person lived, his or her inner life, and an awareness of mortality.
The journey begins with your loved one’s withdrawal from the world and a sense of separation from those who have been so much a part of life. This separation is an important preparation for the patient in saying goodbye. Family members should not take any withdrawal as a personal rejection or consider it any reflection that they are not important or loved. Your loved one is simply changing focus from being involved in life to an inner center of attention. In the search for meaning, visits from friends and family may be less important. The patient may need quiet time to think through how he or she lived, review memories and sort through regrets. It is natural for your loved one to sleep more and lose interest in conversation.
This might be a time of disorientation. Vivid dreams, hallucinations and visions are sometimes part of the personal work that needs to be accomplished before the body is ready to let go. Physical restlessness, pulling at the bedclothes, calling out the names of those who have gone before, or even attempting to get out of bed — all this is normal. Although your loved one’s confusion and agitation may distress family members, remember that they are not personal; they are part of the process and may even be helping your loved one move on.

During this time, caregivers can do little other than to be there for their loved ones. Reassure them, hold their hand. Instead of trying to “make sense,” open yourself to their reality and let them know you love them. Most of all, give them permission to let go.

**Physical Changes**

The physical body has its own way of slowing and shutting down. This can be frightening when seen for the first time. But it is entirely normal. None of the physical changes mean your loved one is suffering. The hospice staff can guide families as to what to expect.

As metabolism alters, food becomes less appealing. Hunger and thirst decrease and eventually disappear. The body no longer needs to maintain itself — it is on a different journey.

“One thing I see families struggle with the most is that their loved one’s appetite diminishes,” says Peggy Durkin, regional vice president of hospice services for AseraCare. “We want to feed the people we love. But when someone is dying, their body doesn’t need or want that food. Families feel so frustrated because they can’t comfort their loved one with his or her favorite meal. We help them understand this is a normal process for the body. It’s not that the person doesn’t want to eat or appreciate what their loved one is trying to do, but sometimes they can’t eat. We help the family find other ways to express their love.”

Changes in vision and speech are common at this time. Your loved one may close his or her eyes due to sensitivity to light and difficulty focusing. Words are
the hallmark of the physical world, and communication now may be reduced to a squeezed hand or a smile. Let the hospice nurse know if you notice any signs of pain, such as a grimace or furrowed brow.

Incontinence, decreased blood pressure and irregular pulse are all signs that the physical body is shutting down. As circulation diminishes, skin may be hot or cold and color alters. Lips, nails, hands and feet may take on a bluish cast. There may be respiratory congestion and pauses in breathing. Your loved one may make a rattling sound or moan. This does not signal pain or distress; it is simply air passing over the relaxed vocal cords.

Hearing may be the last sense to go, so through these changes, talking quietly and lovingly may bring great comfort to your loved one. Avoid loud noises or any effort to “revive” your loved one from the process.

Passing from life is a sacred time. Each person will choose the moment of his or her death. When surrounded by forgiveness and love, letting go of life can be a profound and peaceful transition into a dimension only the traveler will know.
Tips from AseraCare on How to Help Your Loved One Let Go

• Now is the time to give your loved one your full acceptance and support without judgment. Giving permission for the person to let go is the greatest gift you can give.

• Eating and drinking are no longer necessary. Don’t force food or make your loved one feel guilty about rejecting food.

• Hearing is often the last sense to go, so speak directly to your loved one in quiet tones.

• If your loved one becomes restless, do not try to restrain him or her. A cool cloth to the forehead can be calming.

• Discuss with the hospice nurse how to keep your loved one clean and comfortable.

• Congestion and gurgling sounds in the chest are normal and do not signify pain. Gently wipe your loved one’s mouth with a moist cloth.

• As the skin becomes cool from decreased circulation, have a blanket handy.

• Now is the time to say goodbye. Tears are a normal part of the process and express your love, so don’t feel you must hide your tears from your loved one.
• You may want to feel close, so feel free to hold your loved one’s hand or even lie down next to him or her. This is a time of love.

• The actual signs of death are lack of breath and heartbeat, eyelids lightly open, pupils enlarged, relaxed mouth and jaw.

• Death is not a medical emergency in hospice. Nothing has to be done immediately. You may stay with your loved one in this sacred space. When you are ready, notify the hospice nurse.
Bereavement: Healing, Grief and Support

No matter if expected or not, the death of one whom you love generates the most difficult and complicated of human emotions. The void left in our lives is too vast to ever close. Nor should it. Grief produces a powerful tidal wave of shock, denial, anger, guilt, depression, numbness, confusion, overwhelming sadness, fatigue and weakness. You’ll ride deep troughs of despair that he or she is no longer there. Yet from the crests you’ll laugh — humor triggered by a memory, a picture, an object that was special to you both. These emotional ups and downs are frightening. But they’re normal. In time, they will level out into a manageable cycle of regret and joy that will roll like the sea when the storm has passed. We will always grieve for those who have gone before us because they will always be a part of us.

Just as it was our job to accept the transition of death, we must accept grief and allow ourselves to feel and express our emotions. All of us grieve differently. There is no right or wrong way. Society forces on us stereotypes of grief, and we wonder if we are behaving appropriately. One person might ask: “Why am I always tearful? Shouldn’t I be getting on with life?” Yet another might be responding completely differently and worrying that the forecast flood of tears has not arrived. We should not judge ourselves for not expressing grief the way others might feel we should. Rather, we should understand that grief itself is a journey that requires us to be patient with ourselves, to develop our own understanding of how grief affects us, and to have compassion for other family members and friends who are expressing grief in their own ways.
Bereavement begins with the acceptance of the imminent passing away of a person we love. Often bereavement begins with the transition from active treatment of the disease to palliative care, the soothing of its symptoms and the hallmark of AseraCare Hospice. Though death has yet to occur, and may be not just hours but days or weeks away, engagement of hospice marks a profound transition in the way family and friends feel about the future of the person they have loved for such a long time. The onset of the reality of bereavement triggers grief. By effectively addressing issues relating to bereavement before death has occurred, hospice staff prepare families and friends for grief.

**The Five Wishes**

With no family contact for years, the 90-year-old patient relied heavily on her two best friends on whom she had conveyed power of attorney for all legal, health and financial matters. Her friends were in denial. They refused to allow “hospice” to be mentioned in the patient’s presence. The staff at AseraCare Hospice in Bloomington, Mn., was deeply alarmed. The two friends desperately needed help. They were asked to meet with a group that included the facility social worker, dietitian and registered nurse, along with the AseraCare team’s spiritual care coordinator, services coordinator, and registered nurse case manager. The purpose of the meeting was to gently prepare and guide the friends through the dying process. Writes clinical liaison Kathryn Conery, “We believed the patient would not and could not die peacefully until the friends were able to understand and let go.”

“We spent half the day with her friends, gently discussing all aspects of

“The five wishes:

- saying I love you,
- I forgive you and know you forgive me,
- I’ll be OK,
- thank you
- and goodbye.”
the patient’s condition. As a team we discussed the physical, spiritual and emotional aspects of dying. The five wishes: saying I love you, I forgive you and know you forgive me, I’ll be OK, thank you and goodbye were carefully explained,” Conery recalls. “Clearly moved, there were a lot of emotions and tears but the anger had dissipated. There was only the spirit of calm acceptance.

“Following this meeting, the friends went to the patient’s bedside together that evening, and for the first time they were able to honestly and openly give the patient permission to die surrounded by love. A service of ‘commendation of the dying’ was requested and performed, after which, the friends spent several hours following our team’s guidance and were able to give the patient the five wishes. They left late that evening, emotionally spent but at peace. The patient died peacefully shortly afterward with members of the AseraCare team present.”

Forgiveness

William, 88 and dying from bladder cancer, was a most reluctant patient, according to Darrell Miller, executive director of AseraCare Hospice in Akron and Cleveland, Ohio. William was the patriarch of his family, the strong man to whom others came for advice. He didn’t need or want special care, but his increasingly frequent outbursts of rage at first his residence in a nursing home and then hospice while at home indicated to the care team that something was definitely wrong. Just before Christmas, he told his nurse that he wanted to talk with another “guy” about his “soul.”

“I went,” Darrell says, “and we talked about everything — the weather, his late wife, how food hadn’t tasted good since she died, his career, and how he’d come to realize that his family would be OK when he passed on. When he felt that he and I had established a personal rapport, he finally asked: Did I think there was a God or was it all hooey? I pushed the question back to him: Did he think there was a God? He answered softly, ‘I suppose.’

“He asked if God was forgiving. I said, ‘Absolutely!’ His voice dropped and trailed off, and he said ‘I sure hope so…’ And then it came out, all of the war-
time stories and things he had done. When he finished, with tears streaming down his face, he asked ‘So, guy, could God forgive that?’ I assured him in no uncertain terms that God would forgive us if we only asked. He asked me to pray with him. I got up, put my hand on his shoulder. Knowing his fear and his desire to be ‘forgiven’, I simply prayed. ‘God, thank you for forgiving us for the things that we hide from everyone else. Thank you for the time to share as men today, and most of all for being able to allow us to know that you do.’

“On his face was the first smile I’d ever seen from him. I offered to visit him again, but he said he was ‘good’ and would be spending the holidays with his family. He died quietly in his sleep a few days later.”

**Symptoms of Grief**

Grief constitutes the emotions triggered by the onset of bereavement. Each of us responds in different ways.

*Shock* is often the first reaction to loss. The way one may not feel pain immediately after a serious accident, you may feel yourself in a haze as your mind anesthetizes you against overwhelming sense of loss. You may continue your life on “automatic” and wonder why you feel nothing. This natural defense mechanism can carry you through those first few days when there is so much that needs to be done, so little time in which to do it, and even less to come to grips with your loss.

*Anger* is a powerful reaction to being abandoned. It’s OK to resent your loved one for leaving, to feel angry with God for taking your loved one away, and to criticize doctors and even yourself for not doing more to prolong the lost life. Loss is always unjust, and we all look for someone to blame. If you feel angry,
allow yourself to and realize that it will fade. Try, though, not to let bitterness be consuming. It can be a powerful devil. Hospice counseling can help.

**Guilt** is a common emotion when you are confronted with the death of a loved one. You just know that if only you’d done things differently, that person would still be at your side. Many, especially when the departed was ill for a long time before passing away, express guilt about being relieved that the ordeal finally has come to an end. The best antidote for relief-based feelings of guilt is to remember that death released the one you loved from suffering.

**Despair and anxiety** can be overwhelming. Our partner shouldered half of the burden of our life together. Now we’re alone. How can we get through each day and each of the first few months of bereavement without the love, support and knowledge of the one who’s passed away? Take tasks one step at a time. Do the little things first that your spouse used to do … like feeding a pet or setting the thermostat. These small successes will build upon each other, and you’ll regain your confidence. Be shameless yet gracious in taking advantage of offers of help from your friends. They want to give and you need help. Talking with them about your feelings and your challenges is fine tonic for dispelling despair and anxiety.

Changes in behavior will occur as we work through grief and bereavement. You may become irritable or manically joyous as you attempt to compensate for feeling bad. Common, too, are feelings of depression and detachment. Sleeplessness may lead to fatigue and a sense of physical weakness. One may over- or under-eat or drink more than normal. Uncertainty about the future may cause some to hoard and others to overspend. It’s important to stay in touch with your friends and family, and when they ask “How are you doing?” be candid!

Sadness and loneliness accompany grief and they always will. We long for our loved one’s companionship, conversation, laughter and, yes, even disagreements. A patina of sadness and yearning will always tinge memories of her or him. That’s to be expected. Withdrawal only makes longing for the departed
more intense. Spend time with family and friends and find new things to do together. The sadness will be ever present, but loneliness will fade as you continue to pursue life’s dreams.

Remember that young children grieve too, obviously for a parent but also for a grandparent, a favored aunt or uncle, or a close family friend. It’s tempting to shield children from tragedy. Like you, they feel a sense of loss that is heightened when they are not included in the grief process. Discuss death with them gently, but honestly. So doing helps them understand that death is a part of life and may keep them from resorting to unhealthy psychological defenses against grief.

Focus on the Future

A joyous celebration of the life of a loved one brings closure and comfort, and focuses family and friends on the future that the departed wished for the ones she or he cared for. The celebration may take the form of a funeral, a memorial church service or another commemoration of life such as scattering ashes in a place the deceased truly loved.

Dealing with immediate tasks helps channel grief in productive ways. The death of a spouse or child triggers a whole host of legal and financial issues. A hospice social worker can help you sort through the forest of tasks ahead, provide counsel as you set priorities, and steer you to other agencies that can help. Tackling these chores gives the bereaved an important sense of purpose and feeling of accomplishment similar to what they felt as caregiver when the deceased was alive.

Take care of yourself! Some who become despondent after the death of a spouse or other person whom they deeply loved may let themselves go. Keeping up with exercise, eating a balanced diet (or even three meals a day), avoiding reliance on prescriptions or alcohol to blunt pain, sleeping regular hours, and even doing daily chores like dishes, laundry and house cleaning are all important steps that will ensure your good health. Think of it this way, the one you loved cared
deeply about your well-being. She or he wanted you to go on with your life, and good health is essential for making that wish come true.

**Hospice: Your Companion in Bereavement and Grief**

For a year or more after your loved one’s death, AseraCare helps family through bereavement. Professionals and volunteers with special training assist in the development of a healthy grief process. While they are fonts of information and advice, what they do best is listen to you talk about your life with the deceased, learn about your needs and what you would like to do as you go forward. They may suggest that you consider becoming involved in a support group.

A support group is usually made up of 10 to 12 people who have experienced loss of a loved one and who share similar interests. The group meets
regularly, generally as long as the group members find it beneficial. Facilitated by a trained professional, conversations allow the recently bereaved to share their stories, their successes and their challenges. Other members of the group offer hints and suggestions. Most members feel that their support group is a “safe place” where they can be more candid than with family or even close friends. The bereavement counselor can identify a number of support groups that might meet your specific needs.

Each family is unique. In bereavement there is no “one size fits all.” And family situations evolve in the days, weeks and months after a death. Without being intrusive, AseraCare Hospice stays in contact with families. During your loved one’s final days, you will be offered the opportunity to talk with a bereavement counselor. When death occurs, the counselor will ask how she or he can help. You will receive a follow-up call within a few days, and then cards and letters suggesting bereavement activities in which you might be interested. Should you wish, the counselor can suggest books or online articles that might be helpful. The thing to remember is that with hospice, you are never alone.

The Hospice Presence

The patient had been an avid football fan. He passed away in summer, and now that fall had arrived each family member whose life he had touched deeply was trying to deal with their loss. The football season and the holidays that marked its end would be especially trying, as many good memories had been forged during games and holiday festivities.

Carmen Tegels, chaplain at AseraCare Hospice in Omaha, Neb., once taught sewing. She felt she could use her talents and produce a keepsake that would reinforce memories of good times with sports and provide comfort as well. At her request, the patient’s widow provided some of the patient’s favorite clothing that carried logos of his favorite teams. Carmen then created a special pillow for each family member and close friend. A pocket was stitched on the outside of each pillow. Into it was slipped a photo of the patient taken during a moment that
would be especially memorable to each who received a pillow. They were delivered during the height of the season and were an immediate hit with the family. And they provided Carmen with that warm feeling that comes from going above and beyond to care for a hospice family.

**Butterflies and Balloons**

Every year in early November, scores of butterflies or balloons float upwards from Monroeville, Ala., a small town about 30 miles north of Mobile. They’re released by families of patients and staff who’ve passed away in hospice during the year. “We alternate,” laughs the executive director. “You have to keep the butterflies [ordered online] in the refrigerator, then take them out two days before so that they can warm up and fly!”

Attended by more than 200 people, including bereaved families, their friends and hospice staff, the event features music, skits and speakers selected to help families reflect on their lost loved ones.

“We read their names and have a slide show of their pictures,” the director reports. “While families and friends are remembering those who have died, our staff is thinking about how each of them touched our lives and what they did for us. It is a tearful and joyful time.”

**Beyond Bereavement**

Bereavement and grief over the loss of a person who was once so dear to us and so central in our life will always be present. The pain of her or his passing will diminish over time. Yet within us all lives a portion of the departed’s soul. Memories of their presence are reinforced hourly, in the bloom of a flower from a bulb so lovingly planted, in the smell of a favorite food, in a drive down a street past a house you both admired, or in the way fresh flannel sheets feel on that
first cold night of winter. AseraCare Hospice counseling can ease mental anguish over loss but putting bereavement in proper perspective requires personal commitment. Tug McGraw, the awesome left-hander with 1973’s amazing New York Mets, summed it up simply when he said, “Ya gotta believe!”
I’ll have to admit that when Katie (K.T.) passed away, I was pretty despondent. My depression had been growing as her illness progressed. The hospice where Katie had been in residence was eager to help and invited me to participate in groups and talk with staff. Perhaps I should have availed myself of their services. However, completing this book connected me with scores of AseraCare professionals, patients and survivors. I learned their stories and through them reflected deeply on the meaning of dying and death. For me, writing and editing this manuscript has provided a very effective catharsis. I am grateful to AseraCare for the opportunity, and feel that somehow, some way Katie’s spirit laid the groundwork for my recovery. But sustaining that recovery is up to me. So I’ve just completed all those medical tests that gentlemen in their 60s are so wont to avoid. The result was a clean bill of health, which has reduced my anxiety immensely.

On Katie’s death, a friend who has written extensively and professionally about bereavement and grief advised me “not to do anything for at least a year.” That’s not in my ken. The tableau of life has been shifted. For me, embarking on a new path was made so much easier by the planning that Katie and I shared in the months before her death. And when I tell friends of some of the things that Katie and I discussed, I’m amazed at how many long-married couples have yet to talk about those issues. Surfacing them while we had a chance to think through them together has vastly reduced any feelings of worry I might have had over not doing things in a way that Katie would have approved. What she wanted was for the man she loved to continue his life as the caring, self-confident and productive person she married. In her honor, it is at once the least and the most I can do.

– John Ross
Families Say ‘Thank You’

Families whose loved ones have passed away in hospice often find the need to say “thank you” for the care and loving environment provided their loved ones in their last days. Here are some special notes, with the names of patients and families removed for privacy, that express the gratitude of families for the support of hospice staff.

Thank you for the care and respect you gave to our mom/wife. It’s very hard for a person dying to keep dignity, but all of you let her have that. Thank you for being there at the last, for doing what you could. You are wonderful people.

We will always remember your services in a kind and caring way. A special “thank you” [to the staff], they were wonderful. I was so far from home and family these last months and they helped me so much — much like family would.

Many, many thanks for the wonderful care you have given my husband. People may hear about hospice, but they don’t really know how wonderful you are. You are God’s “chosen,” and I will always carry your memory in my heart. Our love and best regards to all of the nurses that came out to help him. We will miss them.
Thank you so much for the attention and comfort all of you gave to [my father] and to his family, both in the weeks preceding and on the day of his passing. Though I cannot say our lives have returned to normal, we are resuming our schedule as much as possible. A service celebrating his life was held, giving the family from out of town the time to attend.

Please pass on our special appreciation to [staff members] who were kind, patient, attentive, cheerful and gentle, and who came promptly at crazy hours and offered physical and emotional comfort. A thanks to [the spiritual care coordinator], who was a wonderful listener and offered quiet reassurance and comfort.

You are all to be commended. We could not have managed the difficult times without you.

Words cannot express the gratitude I have for all of you. I know how well you cared for Dad and your concern for his comfort.

Thank you for making his final months so comfortable and I know I wouldn’t have made that journey as easy as I did without all of you, whether it was just being there on a bad day or listening to his funny stories. Again, thank you so much.

Words are difficult to find to express the gratitude our family has for your unique organization. All of you truly tended to our family with gracious concern I will always remember.
Thank you so much for the food you brought to our home for our mother’s memorial. Thank you all for such a great job you did taking such great care of her.

I want to thank you for your help, kindness and support while Granny was in the [nursing home]. It was such a hard time for me to deal with and you helped me get through it. Thank you for your support when it came to the end. It meant so much.

I wish you well in the future. You’re certainly in the right profession.

Our family wants to let you know what a wonderful job you did in caring for my mother. You were so very caring in her needs and in keeping us informed of what was happening. You made her passing peaceful and painless and our acceptance much easier to bear. Thank you so very, very much for your kindness and compassion.

I could never express in words the gratitude I have for the compassionate care provided to my aunt in her final days. Thank you immensely for all of your support.
Actor, author and healthcare journalist, K.T. Anders shepherded her mother’s passing with the help of hospice in the mid-1980s. Though diagnosed in June 2008 with inoperable lung cancer, a not-unexpected consequence of radiation treatments she received for stage IV Hodgkin’s disease in the 1970s, K.T. accepted the assignment to write this book in the spring of 2009. She felt the hospice way had eased the ultimate life transition for the families of so many of our friends. Indefatigable and blessed with wryly irrepressible good humor, K.T. was totally committed to *The Journey Home, Stories and Insights From AseraCare Hospice* which, as her cancer progressed, she knew would be her last. At Blue Ridge Hospice in Winchester, Va., K.T. passed away early on Christmas morning 2009. Also an author, her husband – John – completed the manuscript by writing chapters on grief and bereavement.