The Hospice Story
Orientation Manual
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It was my very first day as a volunteer for PruittHealth Hospice, and I had no idea what to expect. As a young, healthy, college student, I had the mind set that I was invincible and that I would be healthy forever, as many young people often assume. Little did I know that when I walked into the room to meet my first patient, my views on getting older and my life would be changed forever.

I had been educated about this patient, “She’s feisty,” and I was informed that she had been refusing to eat. Despite my reservations, I sat with the patient for an hour or two talking about any and everything.

The patient I got to know was kind, gentle, and loving. Before I left that day, the patient had eaten all of her food without hesitation, and her nurses were pleasantly surprised. At first it was quite puzzling to me too. Why did she pick today of all days to finally eat? My volunteer supervisor explained that it was likely that I had a lot to do with it.

My heart melted just to think that by simply providing someone with company and letting them know they are cared for, and not at all alone, can make such a difference not only emotionally but physically.

I am proud to say that since that initial visit, I went to see this patient regularly. After only a few months, the patient had improved so much that she was taken off hospice care.

When I first began volunteering for hospice, I had no idea what to expect. I thought that I would make some people smile. I had no idea that I could have the power to change someone’s life. When I think about my future now, I do not see myself as the invincible young person that I was before I began volunteering.

I realize that I, just like every other person in the world, will too grow old. There will be a time when I may have to be in a nursing home under hospice care, and that thought doesn’t scare me because I may be lucky enough to have the love and companionship of a hospice volunteer.

Lynn Bailey Bryant, age 20
East Carolina University Student
PruittHealth Hospice Volunteer
“The word palliative comes from the Latin word ‘palliates’ which means to cloak or to cover. Giving palliative care means to ‘cover someone with care’ – care that covers the whole person like a coat or cover. The word hospice comes from the Latin word ‘hospes’ which means host, and the word host comes from the Latin word ‘hostia’ which means sacrifice. Hospice care in its purest form is offering sacrificial care to strangers – treating them like family, offering them rest and refuge in charity and love.”

Daphne Clements, PruittHealth Hospice Chaplain
As a member of the International Voluntary Service for Peace in 1945, Elizabeth Kubler-Ross went to Poland to work with the sick and starving. At Maidanek in a concentration camp, she discovered symbolic butterflies carved into the walls.

She was so emotionally affected by the place where thousands of children were put to death, that it marked the beginning of her interest and study of death and dying. The butterfly became her symbol for the transformation that she believed occurred at the time of death.¹

Today, the butterfly is the national symbol for hospice care.

Following World War II, as the United States built towns and cities, hospitals became the place for the terminally ill and dying. Before hospitals, families took care of the dying patient in the home, and death was as much a part of a family’s life as the birth of a child. Several generations of families lived together or near one another, and everyone participated in the care-giving and the dying process. Sometimes illness was lengthy (months or years); everyone knew someone who was chronically sick or dying. However, by the late 1950’s, medical practices emerged as the place for treatment of patients and families, and as hospitals grew in size and number, more specialty medical practices developed.

When the patient was hospitalized, the hospital specialists made the medical decisions without input from the patient or family; if asked, no family member or patient would have known what to do. Ironically, (like today) a patient could have several doctors who knew specific medical information about him or her, yet often none of these specialists shared information with one another. It would be many years before conversations about death and dying and alternative options would be a part of the dying patient’s story.²

In 1959 at a Yale University symposium, Dr. Elizabeth Kubler-Ross presented a paper based on her studies of dying patients in U.S. hospitals. Kubler-Ross described the dying segregated from other patients, heavily sedated, and alone, often in a wing of the hospital with other dying patients, without family or friend. Frequently, these patients were far away from the nurses’ stations. She was teaching at the University of Chicago and divinity students started coming to her lectures to ask how they should talk to and listen to dying patients. Soon nurses, and eventually medical students began to appear, asking the same questions.³

From her research and her seminar experiences, she wrote her book, On Death and Dying (1961), which changed the public and medical image of the dying patient. Dr. Kubler-Ross left the university and traveled the U.S. sharing her studies in seminar formats for nurses. She created her own independent university that taught about death and dying, and she became the dying patient’s first advocate.⁴

Eric Cassell, a retired New York physician and Cornell University professor who has written widely on the care of dying and is an advocate for hospice work, says:

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<th><strong>Medieval Times</strong></th>
<th><strong>1800’s</strong></th>
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<td>Hospice was a place where pilgrims could stop for rest, food, and shelter when they were tired, sick or dying. Hospices were scattered throughout Europe and along the way to the Holy Land.</td>
<td>The first hospice created specifically for the terminally ill opened in France in 1842. In 1870, the Irish Sisters of Charity established Our Lady’s Hospice in Dublin dedicated to the terminally ill.</td>
<td>In the United Kingdom every patient with cancer had a general practitioner and a visiting nurse who made home visits, which became the model of Home Health Care. Following World War II, as the United States built towns and cities, hospitals became the place for the terminally ill and dying, removing them from the home and often family.</td>
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“I took care of the dying ... before there were hospices, and people died badly. We never gave enough pain medication. Never.

“In the 1950’s, hospitals avoided the most effective painkillers, such as morphine, for fear of addicting patients - never mind that the patient was going to die anyway. And most doctors never told their cancer patients they had the disease. Because we thought if you told someone they had cancer, then that was the end because they would say, ‘Well, what are you going to do?’ And we would have to say, ‘We don’t know what to do. You know, we don’t have anything to do.’”

At the same time frame in the United Kingdom, Cicely Saunders was a nurse who was working and volunteering at St. Luke’s Hospice and St. Joseph’s Hospice in London. The unspoken rule of her experience in both places was that doctors, chaplains and social workers came and went by the patient’s bed, but the nurse was always left to attend to the dying patient. Saunders understood that dying was a part of life, but she rejected that dying badly was a necessary outcome of a terminal illness. She kept trying to find ways to ease the physical pain of the patient and the emotional distress as she tried to respond to their families. Eventually, she returned to school to get a degree in social work.

For seven years, Cicely Saunders studied drug reactions to the pain of the dying, and she developed pain control management and comfort care for relief of symptoms. She studied the benefits of oral morphine as it controlled the pain of the patient, yet she was frustrated because “the patient had to earn the morphine by having pain, first.”

Saunders tried to get the doctors to understand that there were ways to offer the morphine before the pain was so acute. A friend said to her that the only way she would get the doctors to listen to her was to become a doctor herself because doctors would never listen to a nurse. So at the age of 33, she went back to school to become a doctor, and in 1957, she became the first modern doctor to devote her career to dying patients.

Ten years later in London in 1967, Dr. Cicely Saunders opened St. Christopher’s Hospice, which became the model for modern day hospice care. Dr. Saunders’ identified “total-pain care” by caring for a patient’s physical, emotional, social, spiritual and financial pain; she identified this type of care as the epitome of best nursing practices. St. Christopher’s hospice care marked a new beginning not only for the care of the dying but for the practice of medicine as well.

Hospices in the U.K. grew in the context that every patient already had access to a general practitioner along with a skilled nurse who made home visits. In contrast, hospice programs in the U.S. developed because there was not a home healthcare system; home healthcare became a by-product of the hospice movement.

In 1961 Florence Wald, Dean of Yale’s School of Nursing, invited Dr. Cicely Saunders to Yale to speak about hospice care and to tell the St. Christopher’s story. Wald and Saunders began
a life-time friendship that was centered around hospice work, and Wald started her research on how to offer hospice care in the U.S. In 1966 she invited both Dr. Saunders and Dr. Elizabeth Kubler-Ross to speak about death and dying at Yale. Later that year, Wald traveled to London to St. Christopher’s and stayed 6 weeks to study and work with Dr. Saunders. In both the U.K. and the U.S., doctors were trained in the diagnosis of a disease, and they were entrenched in the curative care model. Unless they heard Dr. Saunders, Dr. Kubler-Ross or Florence Wald speak, no medical professional was educated on how to have conversations about death and dying; no curriculum or courses on death and dying existed in university programs. When faced with the death of a patient, doctors avoided the discussion. Frequently, it was the nurse who helped the patient and the family face the death, but nurses were not trained to talk about death either, and a nurse could not discuss treatment or any other options.

Wald said in an interview with the National Prison Hospice Association (2005):

“See what Cicely had from the beginning was the view that modern medical care, curative treatment and encouraging hope, was not appropriate for persons who cannot be cured... Doctors were unwilling to be straightforward in what they told the patients and the families. If the nurses stepped in and encouraged the patients to frame their questions so the doctors would answer, most often the doctors would tell the head nurse, ‘I do not want that nurse anywhere near any of my patients.’”

“We were struggling with patients, particularly the cancer patients, who were being treated with surgery and with radiation in the hospital. And despite the fact their condition was worsening, the curative treatment was pursued.

“To us she (Cicely) was a nurse, and that was the epitome of nursing. So it was a very, very moving experience for me.”

In 1968, Florence Wald resigned from Yale and took an appointment for a nurse’s research study on the terminally ill. Sponsored by Yale University School of Nursing and a grant, the research team for two years took care of 22 patients in the Yale/New Haven Hospital, in the patients’ homes and in healthcare centers. Wald's published research, A Nurse’s Study, began the modern U.S. hospice movement. Eventually, Wald opened the first U.S. hospice in 1974 called New Haven Hospice which began with hospice home care (known today as The Connecticut Hospice).

Florence Wald in one of her interviews attributes William Sloane Coffin, a Presbyterian minister who was a chaplain at Yale while she was dean of nursing there, with focusing on human rights’ issues including patient’s rights and the role of doctors. Coffin became a leader in the civil rights movement and later an outspoken critic of the Vietnam War.

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<th>1980’s</th>
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<td>1982 Congress made hospice care a permanent benefit for those eligible under Medicare.</td>
<td>2008 The Centers for Medicare &amp; Medicaid Services (CMS) revised the Conditions of Participation (CoP’s) that hospices must meet to participate in the Medicare &amp; Medicaid programs. The revisions emphasize transparency, patient rights, and quality outcomes.</td>
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<td>1989 The Omnibus Budget Reconciliation Act of 1985 and 1989 allowed for the use of the Medicare Hospice Benefit to be more widely available for nursing facility residents.</td>
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“As protestors from Yale’s medical campus intermingled with protestors from other disciplines, a cross-cultural process occurred which eventually challenged the long-held belief in medicine that the doctor was the captain of the team. That was important for nurses. The doctors thought they were doing the patients good by not breaking down their hopes, by never telling them what was actually going on and why they were doing what they did.”

As social trends changed, what Americans had once accepted as truths and traditions changed. Systems, organizations, and values of previous generations were no longer thought to be the only truths or the only way to do something. The private life became public and often political as the 1960’s became one of many protests, which included images of flag-burnings and marches (protesting the Vietnam War and advocating for The Civil Rights Movement). Before this time, suffering was silent, and no one discussed death, especially a soldier or veteran returning from battle. Television changed how quickly news information was distributed. Television provided daily updates of the war and the marches, and breaking news of historical proportions became an every day occurrence.

By the late 1960’s and early 1970’s, television, movies, and the news brought into living rooms, images and stories of suffering never before seen. In this same wave of change, healthcare began to establish the rights of the patient and the right of an individual to have and make medical choices. Discussions highlighting pro-life versus pro-choice and assisted suicide became conversations of nightly news stories as governmental agencies became involved in a person’s right to choose. By the 1990’s, Do Not Resuscitate, Living Wills and the right to hospice care became those news stories.

Meanwhile, in 1973 in Canada with a grant from the McGill University medical faculty, Dr. Balfour Mount and two students conducted a survey of terminally ill patients at Montreal’s Royal Victoria Hospital. The study included narratives about unnecessary suffering of terminally ill patients with commentary from their family members.

“...It didn’t occur to me that I didn’t have a clue about death and dying. I thought, ‘I’m a doctor; I must know everything in the world about death and dying.’ But, of course, I knew absolutely nothing. We (he and his colleagues) had no idea of the dimensions of our inadequacies. There was abysmal inadequacy in the control of pain and all other symptoms. And we’re not talking about stuff that’s difficult in most cases.”

According to a 2002 survey conducted by the National Hospice Foundation:
• 75% of Americans did not know that hospice care can be provided in the home
• 90% did not realize that hospice care can be covered through Medicare

Dr. Mount read Kubler-Ross’ book On Death and Dying and came across Dr. Saunders name and information about her hospice work. He contacted Dr. Saunders who invited him to London to see St. Christopher’s.

“It was ... one of the most stimulating single weeks of my life. Once I saw St. Christopher’s, I saw there were solutions to that unnecessary suffering. ...It was evident to me that was where I wanted to die.”

Returning to Royal Victoria’s, Dr. Mount created a hospice-like ward in the hospital, with a home-care outreach and a bereavement follow-up program. He believed the hospice model was too expensive for Canada (all services at St. Christopher’s were free, funded by private fund-raising, thanks to Cicely Saunders). He called his new creation a palliative care ward, based on the word’s etymology: to
palliate meant to improve the quality of something. By 1976, the palliative care program became a permanent part of Royal Victoria’s Hospital.

“What has surprised me is how little palliative care has to do with death. The death part is almost irrelevant. Our focus isn’t on dying. Our focus is on the quality of living. With palliative care, the patient and their family and loved ones are all cared for. Fears, doubts, relationships, finances, and the need for spiritual care are all considered. Institutional regulations about visitors, food, pets, and other details of daily life are relaxed. When the length of remaining life is beyond the influence of further treatment, the focus is not on curing or the prolonging of life, but on the quality of life.”

Although access to palliative care in the hospital setting is improving year by year, people living with a serious illness will still find significant disparities in their access to a hospital that provides palliative care.

The U.S. Congress added the hospice care benefit to Medicare in 1982 for those who were eligible, which generated organizations across the country providing hospice services to diverse populations in cities and rural environments. The Omnibus Budget Reconciliation Act of 1985 and 1989 allowed the use of the Medicare Hospice benefit to be more widely available for nursing facility residents. By 1999 board certification for palliative care was begun in the U.S.; however, today, a large population does not understand what hospice and palliative care services are or how to access them.

Hospice care has restored for the terminally ill patient a return to an earlier time with the patient and family actively participating in the dying and death of a loved one, if they so choose. Hospice care is a patient-centered approach that addresses the personal, physical, psychosocial, and spiritual needs of both the patient and family. Without regard for age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay, hospice services offer palliative care for the dying patient and his/her family.

Today hospice:
- Provides care according to the patient’s wishes
- Gives emotional support to the patient and family
- Provides assistance with financial decisions and end-of-life issues
- Makes the patient comfortable by directly treating pain and symptoms
- Provides spiritual support to patients and families for all religious beliefs
- Offers bereavement support from the first day of admission until 13 months after the patient’s death

Palliative Care

Palliative care is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, or slowing the disease’s progress, rather than providing a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious, complex illness. Non-hospice palliative care is not dependent on prognosis and is offered in conjunction with curative and all other appropriate forms of medical treatment.

Today, both “hospice” and “palliative care” have evolved to describe the same concept of holistic care that aims to relieve suffering and improve the patient’s quality of life for however long that life is. When death is inevitable, hospice care seeks neither to hasten nor to postpone it. Rather hospice care chooses to make the remaining time of the patient’s life to be as pain-free and as comfortable as possible.
All of these hospice programs evolved from the work of Dr. Cicely Saunders and St. Christopher’s Hospice.

Today, the hospice movement is widely accepted as another medical alternative or option, a transition to another level of care for the dying patient. Hospice represents a hope and belief that provides for a dignified death that is pain free and comfortable with the patient surrounded by their loved ones, who are educated and supported by a team of hospice experts.

Four pioneers of hospice history lives intersected; together and separately, they changed the way the medical field educates, treats, and supports dying patients and their families nationally and internationally.

**Dr. Elizabeth Kubler-Ross**, with her research, books and lifetime search for education and answers for dying patients changed the way medical schools train doctors and nurses, and educated the world about death and dying (U.S.)

**Dr. Cicely Saunders**, who spent years listening and working among the dying, created and changed pain management techniques for dying patients as well as for medical teams. With St. Christopher’s Hospice she created the model of hospice work that has grown internationally (U.K.)

**Florence Wald**, who trained nurses and understood how often the nurse handled the dying patient and the family, created the first U.S. hospice and became the advocate for hospice services in this country for homes, healthcare centers, hospitals and prisons (U.S.)

**Dr. Balfour Mount**, who developed a way for hospitals to offer comfort measures palliatively and created the model for hospice inpatient units (Canada)

Each in her or his own way saw a need and met that need with a passionate desire to make death easier, not only for the patient but for the family members and caregivers as well. Because they collaboratively shared their research, their work, and their patient’s stories, an entire movement of comfort care developed into what we know today as holistic palliative hospice care.

“They cared about people in pain. By identifying much-needed changes in care of the terminally ill, changes that society embraced, they gave birth to a worldwide movement.”

— James E. Mattson

In 2010 the National Hospice and Palliative Care Organization (NHPCO) estimated that 41.9% of all deaths in the U.S. were under the care of a hospice program. And that in 2010 there were approximately 5,150 hospice programs in the U.S.
The Meaning of Hospice

For as long as I can remember, the word “hospice” was an ugly thing, a place to go to die. It meant that nothing else could be done, and you simply waited for the end. Hospice was a place for when your life was over, one that you couldn’t escape from. My great-grandmother went to a hospice facility, and she didn’t come back home again.

When I was 23, my grandmother was diagnosed with her fourth bout of cancer, and my mother admitted her to hospice. I didn’t want to hear that word because it meant our fight was over. It meant that we had lost.

The local hospice began making visits to my grandparents’ home, which I didn’t know was an option. They made respite visits for my mother, who was the sole caretaker. She would greet the hospice workers tearfully at the door relieved and grateful to have a break for a few hours. My mother would call the hospice nurse at all hours of the day with concerns and questions, and many times, one of the staff would come out to reassure her that my grandmother was okay. They sat and read to my grandmother and made her smile and laugh. They knew her by name. They became her friends, and I believe each one genuinely loved and respected her. They came to the house to support my family when she finally slipped into a coma. They came to her funeral after she died. They supported my family through one of our most difficult experiences, and for the first time, hospice seemed like a glowing light in a dark room.

I began volunteering for hospice at the end of that year. I needed volunteer hours for my medical school application, and I spent a long time considering what I wanted to do. As I began asking around for suggestions for volunteer opportunities, that word came up again - hospice. I remembered the hospice staff that worked with my grandmother, and how much of a difference they had made to my family, and I found myself wondering, “Could I do that too?”

I realized that I wanted to help someone the way I had been helped.

It all happened very quickly - I met with the Volunteer Coordinator and within a few days, I was driving out to meet with my first patient. I was incredibly nervous, What would I say? Would I know what to do?

My first patient was a small, elderly woman, with a sharp sense of humor, and an adamant yet generous personality. I visited her every Monday, and as the weeks turned to months, I learned more about her. We sat and talked, and she shared memories with me, mostly about her family, and when she described them, I felt I could almost see them as she did.

I enjoyed hearing her look back on her life with a mixture of pride and regret, triumph and sorrow. Her memories seem to me like bright lights that won’t fade, even after she’s gone. It wasn’t until my grandmother’s cancer that I learned that dying and death are two separate things, each to their own. However, after volunteering for hospice, I learned that dying was something that could be done well, with compassion and dignity.

And from my first patient, I learned that someone who was dying could have so much life. Walking with someone through the last days of life doesn’t have to be ugly, as I thought when I was a child, or a hardship or difficult. Instead, I’ve learned what it truly is - an honor and a privilege.

Lily Trout
Hospice Volunteer
PruittHealth Hospice of Eastern Carolina
“Hospice care recognizes dying as part of the normal process of life, so hospice care focuses on maintaining the quality of the remaining life.”

Marcia Lattanzi-Light
Hospice Ethics for Patient’s Rights

- To Respect Autonomy: which allows the patient the right to decide how they live their lives and how they make medical choices and decisions
- To Do No Harm: which is the obligation of all healthcare workers to avoid inflicting either physical or psychological harm on anyone
- To Benefit Others: which is an obligation to improve and enhance the welfare of others
- To Be Just: which is appropriate and equal treatment for everyone
- To Be Faithful: which is to tell the truth, to be loyal and to be respectful and to always honor the dignity of the patient, family and caregiver

Most hospice care plans require several disciplines to intervene, address and resolve identified problems. For example, when pain is identified as a problem:

- The nurse oversees the medication regimen (with coordination with the physician, nurse practitioner and pharmacist)
- The social worker may provide counseling and teach coping techniques
- The chaplain may offer prayer and pastoral support
- The CNA offers personal care
- A volunteer could spend time with the patient reading to her/him, offering respite care for the caregiver, who would be free to do something else.

In order for an interdisciplinary team to function optimally, all members’ contributions are respected and valued equally. The IDG is not a hierarchy of disciplines where some team members have higher rank and importance. Each hospice team member has valuable information and expertise to share, and each is trained to voice his/her observations and recommendations.

Holistic Approach

Hospice care takes a holistic approach that treats the “whole person” and recognizes that, although the physical illness is what brings our patients to hospice, their spiritual and emotional well-being are also our utmost priorities.

Hospice care requires the cooperation of an interdisciplinary team to accomplish quality, end-of-life care. Interdisciplinary means that team members collaborate and leverage their skills and expertise to provide holistic interventions for hospice patients and families. PruittHealth Hospice is composed of interdisciplinary teams of nurses, social workers, chaplains, certified nursing assistants, volunteers, and physicians who provide holistic care to our patients and families. Each team member has expertise in identifying the problems, needs, and strengths of the hospice patient and family. The interdisciplinary group (IDG) utilizes the strengths of every staff member to develop individualized care plans which address the unique needs of each patient and family.

Initial Plan of Care (IPOC)

The purpose of the Initial Plan of Care is to identify the patient/family needs and determine the scope and frequency of services. The Initial Plan of Care (IPOC) is generated by the nurse who admits the patient to hospice.

The Hospice Care Plan

When a patient is admitted to hospice services, team members collaborate to produce a care plan within the first five (5) days of service. The care plan is created with input from the patient, family members and the team’s assessments.

The care plan consists of:

- Problems identified by each discipline
• Realistic, measurable goals
• Interventions to help achieve these goals
• Assignment of responsibility for each intervention
• Individualized goals and interventions

Hospice Care Plan in Healthcare Centers

When a hospice patient resides in a skilled nursing facility, called a healthcare center (HCC), the hospice team is required to coordinate the patient’s care plan in conjunction with facility staff. Effective collaboration about the care plan is essential to ensure that both the hospice and HCC staff provide palliative services that are appropriate for the patient and family.

There cannot be two separate care plans but rather one integrated care plan that blends interventions from all staff who are providing patient care. The hospice staff is responsible for providing palliative case management and must take the lead in coordinating the care plan with HCC staff to ensure that all interventions are appropriate and consistent with hospice philosophy.

The patient and family care plan is an ongoing “work in progress” and must be updated and revised to reflect significant changes in condition, resolution of problems, and new problems as identified. Quality hospice services require continual reassessment of the patient/family needs and their abilities in coping with the terminal illness. The care plan must remain current in order to serve as a relevant tool that directs the course of hospice care.

Weekly IDG team meetings review patient care plans, assess efficacy of treatment, and make necessary adjustments. Care plans are reviewed every 15 days or when any significant change occurs or new problem arises.

The Hospice Team

Administrator:
As director of the hospice office, the administrator is responsible for the operational and financial aspects of hospice care that includes the hiring of staff, the negotiation of vendor contracts that provide auxiliary services to hospice patients, and the management of day to day procedures.

Admission Nurse:
An admission nurse is a registered nurse who makes the first patient visit, determines the appropriateness of the patient for hospice services, and completes the hospice admission. Often the admission nurse is the first hospice contact with the patient and family.

Attending Physician:
The patient’s physician is often the one who has generated the medical order for hospice services, and sometimes he/she remains as the primary care physician for the patient. Throughout the hospice experience, medical care continues to be prescribed by the patient’s attending physician. The case manager works directly with the patient’s attending physician keeping him/her

Caregivers have a unique role to play in an individual’s struggle with life-threatening illness. That role might be compared to a candle.
A candle can help illuminate an experience, provide a path in the darkness, and give courage to explore. Caregivers, at their best, can provide that light.
That light can accompany individuals as they negotiate a sometimes treacherous and scary path.
The journey may still be dark, but the light can make it less terrifying.

- K. J. Doka
informed of the patient’s condition and any change of status. Also, the attending physician prescribes medication needed to keep the patient comfortable.

**Bereavement Coordinator:**
Bereavement is the period following the death of a patient when grief and loss is experienced. Bereavement services begin the day a patient is admitted to hospice service and care is provided for 13 months after the death of a patient to family members or caregivers. The Bereavement Coordinator is trained to offer grief support through phone calls, letters, support groups, and personal visits.

**Case Manager:**
Skilled Registered Nurses trained in pain and symptom management provide hospice care to patients. Case managers monitor the patient’s condition, provide education to patients and caregivers, and inform the hospice team of patient status and needs. The case manager offers medical equipment (DME) and pain management medication as needed for comfort care. A hospice nurse is available 24-hours a day, 7 days a week to patients and caregivers.

**Certified Nursing Assistant (CNA):**
CNA’s, also called Hospice Aides, provide for the patient’s personal care (dressing, bathing, shaving, etc). Their hands of service keep the patient clean and groomed, which provides comfort and dignity for the patient and offers support and education to the family and caregivers. CNA’s may assist with feeding the patient, when needed. Because of the frequency of contact with the patient (personal care needs are determined by the case manager and the family’s requests), the CNA sometimes becomes the strongest emotional contact with both the patient and family.

**Chaplains:**
Chaplains offer spiritual care in accordance with the wishes of the patient and family, often coordinating with the patient’s clergy or religious leader. Hospice chaplains are trained to focus on the patient and family’s spiritual needs and are experienced in discussing end-of-life issues. Chaplains are available to assist in funeral planning and may be involved in the bereavement care. Chaplains do not evangelize but rather support the patient in his/her own end-of-life journey.

**Community Relations Representative (CRR):**
A CRR educates families, physicians, and medical staff about the benefits of hospice services for patients and families. A CRR is involved in community events to educate and promote awareness of hospice services. Sometimes, a CRR is the first hospice contact for the patient and family.

**Director of Health Services:**
The responsibility of the Director of Health Services is to oversee the provision of care provided by the clinical team. The focus is to ensure clinical best practice is utilized by the hospice clinicians to promote quality care and quality outcomes for our patients and families.

**Medical Director:**
A Medical Director certifies that a patient is hospice appropriate based on diagnosis and prognosis. He/She serves as a liaison with attending physicians and case managers for hospice patients; sometimes the Medical Director becomes the hospice patient’s attending physician. The Medical Director attends interdisciplinary team meetings (IDG), reviews patient care plans, and adapts pharmacology orders to the patient’s change of status, as needed.

**Nurse Practitioners:**
Nurse practitioners are an integral part of hospice care because of their unique ability to see the patients from both a nursing and a medical perspective. Their advanced training in nursing, coupled with their foundation in the basic doctrines of nursing care, means that they can play
an essential role as a liaison between the doctors and nurses on a hospice care team. Hospice nurse practitioners often take on the duty of assessing patients after 6 months to determine whether or not they still need to receive hospice care, then working with medical directors and physicians to determine a course of action.

**Patient and Family:**

The patient, family, and caregivers are the center of all hospice care. Patient care begins when the patient makes decisions about what they want hospice care to be for him/her. The hospice team listens and responds to the patient’s needs, concerns and requests. Each discipline offers resources to the patient and family to help maintain comfortable palliative care through the end-of-life.
THE HOSPICE PHILOSOPHY

Pharmacists:
Pharmacists coordinate pharmacotherapy by making recommendations for appropriate therapy, educating patients and the hospice team about medications, monitoring therapeutic responses, and performing other medication-related functions. Pharmacists maintain patient medication profiles and monitor all prescription and nonprescription medication use for safety and effectiveness.

Social Workers:
Hospice social workers conduct psychosocial assessments and provide counseling, education, and other skilled interventions to enhance patient and family coping skills. They are knowledgeable about financial and community resources and often link patients and families to sources of practical assistance. Hospice social workers support patients and families throughout the grieving process and routinely assess the bereavement risk of family members. Social workers assist patients with advance care planning, including designating health care or financial powers of attorney and making decisions about Do Not Resuscitate (DNR) orders.

Social workers advocate for patients’ self-determination and attempt to honor patients’ wishes about end-of-life care whenever reasonably possible. They assess the strengths of the patient and their family system and incorporate these positive components into the individualized plan of care.

Volunteer Services:
Trained, certified hospice volunteers provide companionship and respite services to patients and families, often determined by the “gifts” of the volunteer as well as the requests of the patient or family member. In the home and healthcare centers, volunteers offer companionship for the patient that often translates into a connection with a patient’s roommate and the staff at the facility as well. Sitting and visiting with a patient, taking him/her outside for a stroll in a wheelchair, reading to a patient, providing music, taking magazines and flowers are all examples of comfort care that volunteers provide faithfully in the home or healthcare setting.

Also, volunteers may offer respite care for the caregiver (time away from the patient for an appointment, shopping, or rest). Volunteer services are based on patient need and request as assessed by the Volunteer Coordinator Interdisciplinary Team.

Levels of Hospice Care

There are four different levels of hospice care: routine care, inpatient care, continuous care, and respite care. Each type of hospice care is designed to meet the needs of the hospice patient and family.

Hospice care is provided by all disciplines offering specialty support and education wherever the patient lives.

Hospice volunteers can volunteer in any of these settings of hospice care; each volunteer selects where and how they want to serve.

Routine Hospice Care in the Home:
Often the patient and family want the patient to die in the home and are willing and physically able to care for the dying patient in that setting.

The hospice team including the volunteer makes regular visits to the patient providing care as needed. Sometimes the patient wants to die at home, but the family, especially the caregiver, can not offer this care on an extended basis. The family may request that the patient be transferred to a more appropriate setting for the final days of life.

Routine Hospice Care in the Healthcare Center:
Healthcare centers (once called nursing homes) offer long-term care for elderly and disabled adults. The hospice team provides care to the patient in the healthcare center offering all the same services, education, and support that is offered to the hospice home patient.
Inpatient Care:
Inpatient care is designed for pain control and symptom management that cannot be fully addressed in the home or healthcare environment. Often once the pain or other symptoms are managed and under control, the patient may return home or back to a healthcare center.

Peachtree Christian Hospice in Duluth, Georgia ([http://www.peachtreechristianhospice.com](http://www.peachtreechristianhospice.com)) is the Atlanta metro area inpatient facility managed by PruittHealth Hospice. In other areas of the state and in other states, PruittHealth Hospice has contracts with inpatient units and local hospitals to provide this level of care for our patients.

Continuous Care:
Continuous care is designed to provide skilled nursing care during times of crisis or for pain and symptom management. This care is provided in the home or in the healthcare center in order to avoid hospitalization. Continuous care is provided for at least 8 hours in a 24 hour period.

Respite care:
Respite care is designed to offer the home caregiver a temporary relief (time out or time away) from the duties of caring for the patient. Volunteers are often the first resource for respite care; however, when 24/7 care is needed, a sitter service can be hired by the family to provide extra respite care. In addition, Medicare will pay for respite care for a period of 5 consecutive days to allow the caregiver a break. Hospice volunteers can volunteer in any of these settings of hospice care; each volunteer selects where and how they want to serve.

Hospice Eligibility and Payment
For a patient to be eligible for hospice care, certain conditions must be met:

- Regulatory guidelines certified by a physician stating that the patient has 6 months or less to live if the disease follows a typical progression
- A referral, a medical doctor’s order, must be written by the patient’s attending physician
- Patient must be evaluated by a hospice admission nurse and determined to be hospice appropriate
- Using guidelines established by medicare

When the patient elects the hospice benefit, direct hospice services are covered: case manager, social worker, chaplain, certified nursing assistant (CNA) along with prescription medications, equipment and special medical supplies related to that terminal illness.

After a patient elects the hospice benefit, he/she is eligible for a 90 day benefit period, another 90 day period, then 60 day benefit periods until death. The attending physician and the hospice medical director must certify and recertify at the end of each of these periods that the prognosis has not changed.

A patient may improve significantly or decide to pursue aggressive curative treatment. At that time, he/she would choose to revoke the hospice benefit. He/she also will forfeit any remaining days in the existing benefit period. If he/she chooses to re-elect the hospice benefit, he/she would return to the hospice program in the next benefit period.

Payment:
Hospice Services includes:

- Physician
- Nursing
- Social Work
- Spiritual Care
- Counseling
- Pharmaceuticals
- Medical Equipment
- Bereavement support
- Volunteers

Hospice services are comprehensive and are available twenty-fours a day/seven days a week.
A quick nod. A long blink. This was the entirety of my first conversation with one of the residents at one of our healthcare facilities. Entire minutes of silence became a staple as I waited for any kind of response. After the first couple of visits, I was convinced that she didn’t like me.

Two visits later, as I was settling into the assumption that she’d rather I read to her than try to talk, I noticed a Whoopi Goldberg movie sitting on her nightstand. I wasn’t expecting a response as I made the passing comment that Whoopi always dressed in the craziest get-ups. Imagine my surprise as she smiled, turned her head to look at the movie and nod “yes.”

Asking if she’d seen the sequel to the movie, I received an answer; a long blink “no.” This brought about the realization that quick nods and long blinks were not her trying to dismiss my visits, but rather, her way of communicating with me. Although she would say a word or two occasionally, after 5 months I’ve learned so many of her mannerisms that we can now have entire conversations about movies, shows, food, family, and the Bible, which I read to her every visit.

I’ve often been told that the most important gift that God gave us was our ability to think for ourselves. If there is one thing I’ve learned from my time volunteering with PruittHealth Hospice, it’s that our ability to communicate those thoughts to those that share want to share it with is just as important.

Being part of a team with so many individuals dedicated to the service of others gives me an unmatched sense of purpose. I often remember the words of my Volunteer Coordinator on our first meeting. “It’s a constant learning process. Keep asking questions and you will never stop learning,” she told me as she took me to visit my first resident.

From visiting patients at healthcare centers to seeing patients at their home, I’ve met some of the most remarkable people, both residents and fellow team members. I’ll never forget walking through the halls and meeting the residents and workers for the first time with Sarah Lottes, a fellow volunteer. Sarah’s willingness to meet with me and to share her experiences as well as to offer advice whenever I ask, demonstrated to me the real dedication of hospice volunteers. She set the standard that I strive for every time I visit patients. This experience, with the selfless character of those I work with and the resilience of those I visit, has enriched my life. I will always cherish the stories told and the memories shared. They are my inspiration to continue the learning process and to continue to serve in this hospice ministry.

Joseph Sebastian
PruittHealth Hospice of Atlanta
“Those who learned to know death, rather than to fear and fight it, become our teachers about life.”

Elizabeth Kubler-Ross
Patient’s Rights

Hospice care is founded on two basic principles: the patient has the right to choose how he or she spends the time left, and he or she has the right for the remaining time to be as peaceful, pain-free and comfortable as possible.

It is the right of each patient to accept or refuse medical treatment. The hospice role is not to agree or disagree with a patient’s decision, rather to honor the right of the individual to make that decision.

The patient has the right to determine his or her course of care, and the patient has a right to take part in that treatment. The desires, hopes, needs, and wants of the patient direct the hospice team, and the hospice team’s approaches and responses are formulated to meet those needs and requests.

Quality of Life

The hospice team assesses the patient’s and family’s perception of what constitutes the quality of life and formulates a care plan based on that understanding. Quality of life is what the patient determines is important. Patient satisfaction with his or her quality of life impacts the satisfaction with the hospice care. Quality of life is subjective and varies from patient to patient and is intertwined with each patient’s level of hope.

In the terminally ill patient, hope is the difference between the desires and expectations at that point in time, and that individual’s reality of existence and experience. A patient’s hope changes and transforms as the terminal illness progresses. For example, a patient may initially hope for a cure and a prolonged life but gradually comes to a greater realization that this hope is unlikely to occur. Then the hope may be for the opportunity to spend time with family and friends before death occurs, or it may be to die without pain and with dignity.

Pickett and Yancey in their book, Cancer Nursing: A Comprehensive Textbook (1996), identify components of physical, psychological, social, and spiritual well-being:

This is the focus for the hospice interdisciplinary team, and these areas are reassessed during the patient’s hospice stay to enhance the patient’s quality of life.

1. Physical Well-Being
   - Multiple symptoms due to disease progression, debility, organic, and metabolic changes
   - Ability to provide self-care
   - Pain
   - Nausea/vomiting
   - Lack of appetite
   - Dyspnea
   - Delirium, restlessness, or agitation
   - Fatigue, weakness, immobility, or sleep changes
   - GI disturbances (e.g., constipation or diarrhea)
   - Urinary incontinence

2. Psychological Well-Being
   - Anxiety or fear
   - Depression
   - Loneliness
   - Suffering or despair
   - Dependency
   - Decreased self-esteem or self-respect
   - Guilt or anger
   - Adjustment to the disease or prognosis
   - Satisfaction with care
   - Denial or acceptance
   - Acceptance of loss

3. Social Well-Being
   - Sense of burden on family
   - Loss of control over life
   - Relationships with others
   - Changing family roles, status, or family structure
   - Family interactions or conflict
   - Fear of abandonment or isolation
• Financial concern
• Diminished leisure activities
• Employment status or workplace relations
• Sexuality

4. Spiritual Well-Being (Sense of Self)
• Religion (practices, rituals, prayers, or meditation)
• Relatedness to God (Superior Being/Higher Power)
• Meaning of life/Existential concerns
• Reason for events
• Purpose of life
• Belief in a primary force in life
• Hope (based in reality)
• Forgiveness or acceptance
• Transcendence
• Redefines views of life
• Redefines relationships
• Feelings of uselessness
• Spiritual needs may vary and fluctuate with changes in physical symptoms

Each member of the hospice team serves a terminally ill patient to die comfortably. Ferrell suggests the following methods to enhance the quality of life for the terminally ill patient and their family members (End of Life Care Content Guideline, Strengthening Nursing Education to Improve Pain Management at End-of-Life-Care. (1999).29

• Effective communication and listening
• Stress management and utilization of effective coping mechanisms
• Sufficient resources and support
• Resolution of conflicts
• Completing unfinished business
• Maintaining ‘non-illness-related’ aspects of life
• Taking one day at a time
• Coping with anticipatory grief
• Defining attainable goals
• Engaging in spiritual practices
• Conserving energy to meet demands
• Exploring losses and their meanings
• Leaving a legacy (e.g. book or videotape of memories)

Once physical symptoms are managed effectively, a hospice patient can focus on other aspects of well-being. Attention to symptom management cannot be overemphasized. These activities focus on resolution of past problems, adjustment to the illness, reorganization of activities to meet demands and life-enhancing practices.

Advance Directives

Advance Directives are written instructions that relate to health care decisions by a patient that guides his or her care if or when he or she no longer has decision-making capacity. These decisions include instructions about the types of treatment wanted or not wanted.

If a person can no longer express his/her wishes, an advance directive provides family members, caregivers, and doctors with the patient’s end-of-life guidelines.

The first step to an advance directive is for the patient to know what he or she wants and then to document those decisions. Next, explain those decisions to family members and caregivers. Some of the most complicated hospice work happens when patients have not made these healthcare decisions in advance, and this responsibility is transferred to family members or care-givers who are the healthcare power of attorney. Because the patient has not clarified in writing his or her wishes, the...
patient’s family members may have opposing opinions and different perspectives about the type of care needed based on care as they understand it.

The Terri Schavio case is a classic example of this type of complication.

Interpretation of another person’s last wishes is often complicated by the fears of loss and pain associated with the patient’s impending death. Therefore, the more conversations and decisions the patient and family and caregivers have before these decisions are needed, the more likely the patient’s requests will be honored.

The way to prevent this conflict from happening is to make these healthcare decisions with family and caregivers long before they are needed. Advance Directives should be just that: directives that are the patient’s wishes that the family and caregivers understand and honor.

**Georgia:**
As of July 1, 2007, there is one legal form that qualifies as an advance directive:

The Georgia Advance Directive for Health Care incorporates the concepts of a living will and durable power of attorney for health care or health care agent into one seamless document.

Research your Georgia state government website for the latest updated forms.

**South Carolina:**
South Carolina provides by statute for two types of Advance Directives:

1. Living Will

The Death with Dignity Act authorizes competent adults to express their wishes regarding the use or withholding of life-sustaining procedures, including artificial nutrition and hydration, in the event they are diagnosed with a terminal condition or are in a state of permanent unconsciousness and in the further event that they are incapacitated or otherwise unable to express their desires. The Act creates a statutory form for this purpose entitled “Declaration of a Desire for a Natural Death.”

2. Health Care Power of Attorney

Sections within the South Carolina Probate Code authorize competent adults to designate another person to make decisions on their behalf about their medical care in the event they become incapacitated. The Code creates a statutory form for this purpose entitled “Health Care Power of Attorney.” For competent adults wishing to express their desires concerning future mental health treatment, the Department has developed a form entitled “Statement of Desires Regarding Mental Health Treatment and Care” for use as an addendum to the statutory “Health Care Power of Attorney” form.

Individuals may also have prepared other forms of Advance Directives or put into writing their desires concerning certain types of medical care.

Research your South Carolina state government website for the latest updated forms.

**North Carolina:**
The NC Secretary of State’s office has established an on-line registry that allows NC residents to file up to four different advance directives, such as a living will, durable power of attorney or health care power of attorney.

Research your North Carolina state government website for the latest updated forms.
Emotional Support for Hospice Patients

Dr. Elizabeth Kubler-Ross in her book *On Death and Dying* identified five psychological stages of dying which have been called the stages of grief. All patients may not experience any or all of these stages and may move back and forth between stages.

Signs of emotional distress in patients, family members and caregivers are important elements in hospice volunteering.

**DENIAL**

Denial is the refusal to accept reality and grows out of shock:

“I don’t believe it”

“You must have made a mistake”

“This can’t be true”

When we receive news too painful to absorb, we use denial to protect ourselves, to buy time so we can adjust to a new and grim reality. 31

Denial is often expressed in behavior:

• Getting a second opinion or several second opinions
• Refusing or forgetting to take medicines
• Not keeping appointments for treatments

How to respond:

When your patient talks about getting better and going camping, you could say:

“Wouldn’t that be fun!”

“I bet you’d like that.”

“Do you have memories of another camping experience?”

Friends and family often engage in denial longer than a dying patient. A strange conspiracy arises in which everyone pretends the patient will recover. It takes tremendous energy to sustain this fiction, an energy that is in short supply for the one who is ill and for the family as well.

The weight of another person’s denial adds to a patient’s burden, often causing a dying patient to withdraw from those in denial, increasing his or her sense of isolation.

**ANGER**

“We’re not talking about that.”

“Why me?”

No matter how it is directed, most anger will be expressed to those who are closest and safest: family and friends. Think of anger as a feeling that develops from another emotion. In terminally ill patients, the roots of anger often are frustration, resentment, or fear. 32

How to respond:

The patient’s frustration stems from helplessness at losing control and becoming dependent on others. This resentment from seeing other’s lives going on, and the fear from the uncertainty about what dying is like adds to this mix of emotions.

It is very hard to avoid feeling hurt when someone lashes out at you.

Whenever possible, give the dying patient choices and control.

Respond to the frustration, not to the anger:

“I imagine it’s hard to have to ask for help all the time.”

“This seems as if it’s very frustrating for you.”

Remember, anger may grow out of the fear of dying or from unfinished business.

**BARGAINING**

The easiest way to understand the bargaining aspect of dying is to watch a child at bedtime (one more hug, one more story, one more drink of water). 33

Dying patients do the same thing as they postpone the inevitable. They bargain with God. If they don’t believe in God, they bargain with anyone they think might have the power to extend
life a little longer. Most dying patient’s bargains go unnoticed; often the bargains remain secret.

If the subject is brought up, listen with respect and say something like:

“Wouldn’t that be great?”

“We’ll help in any way we can.”

DEPRESSION
A dying patient’s depression grows from the loss and grief which has two parts:
Mourning what’s lost already to illness
Health, family role, job, independence…
Mourning what will be lost when they die
Personal relationships, life and future…

These feelings of sadness and depression should be honored, not dismissed or diluted. Listen, be present. No answer is needed, you can only attempt to understand.

ACCEPTANCE
The acceptance of impending death comes detachment, a drawing away from others no matter how close they have previously been. Your patient has accepted the impending death, you may experience mixed emotions because you may see him or her withdrawing from all the activities.

This withdrawal is often painful for those being left behind.

While all of us experience loss, not all of our responses are uniform and predictable.
As a volunteer, you will experience different emotions and responses to each patient’s grief. One of your most important roles is to be sure that you do not allow your previous grief experience to surface into your patient and family’s current grief.

Emotional Needs of Hospice Patients

While each person’s journey towards death is different, there are human needs that we all experience, especially at the end-of-life. This overview from Hospice Foundation of America, The Dying Process: A Guide for Caregivers defines some of those emotional needs.

As a volunteer, meeting those basic needs can make a difference in the volunteer experience for the patient and for you.

Love, Intimacy and Affection:
The feeling of being loved and accepted is universal.

Touch:
Touch is a need from infancy to old age because it conveys caring and love.
You can offer a patient touch by hand holding, pats on the back and hugs. Touch is especially important to non-verbal patients. Always ask permission first.

A Sense of Belonging:
All of us need to feel that we belong in some way.
Patients are members of a family which is the primary unit of care. Hospice team members become another unit of care.
One of the fears of patients is the fear of dying alone or being abandoned.

Meaningful Roles:
Patients have fulfilled numerous meaningful roles throughout their lives. Often those roles, (head of the household, mother, father, president of the company, teacher, pastor, etc.) define who they are, how they see themselves, and how others see them; therefore, the fear of the loss of that role may be overwhelming. Patients may continue these roles as long as possible.
Control:
As human beings it is vital to have as much control for as long as possible to maintain some modicum of dignity. Hospice offers the patient the opportunity to be involved in his/her care issues and decisions.

Independence:
Independence involves being able to do things for one’s self without assistance from someone else. Some of us have lived independently all of our lives and have no practice or experience in asking for help or in relying on someone else to do things for us. Most hospice patients require assistance performing even the most basic and personal of tasks which can be humiliating for some and cause feelings of diminished self-worth for others.

Volunteers need to resist the urge to assist with activities that the patient is able to do. Also, volunteers can promote adaptations of the environment to allow the patient to work within his or her own limitations.

Dignity:
Dignity is both a need and a right intertwined with our self-esteem as it relates to the way others see us and how we see ourselves.

Hospice services make every effort to help the patient retain as much dignity as possible during the dying process.

Stimulation:
Volunteers can stimulate patients physically through touch or create interaction through conversation; both are especially important for non-verbal patients. For instance, music may serve as a way to stimulate memories, conversations, and movement.

Communication:
Talking about death may lessen fears about death. The dying patient has the right to express emotions about the approaching death in his/her own way, or not at all. For instance, a dry erase board may be used if the patient can’t respond verbally.

Leaving a Legacy:
Leaving a legacy is an important need for some patients, and often it helps with thoughts of the impending death if they feel that they are leaving behind a part of themselves. Volunteers can assist the patient in creating a memory book, a work of art, a scrapbook, or even a tape recording or video.
When I arrived at the hospice parking lot, I noticed a local church bus parked in the driveway. As I entered the front door, I heard a nurse say to someone else, “you need to go over to unit two.” I asked why, and she responded, “you’ll know when you get there.”

As I rounded the corner, there was wonderful music coming from down the hall; old time gospel hymns and voices blended with musical instruments vibrated over the hallway. Patients and guests were coming out of their rooms to be closer to the musical sounds. The last room in the hallway was packed with elderly visitors holding their hymnals singing all those songs that I’d grown up hearing.

A lady seated near the doorway looked up at me and said, “that’s my mother in there in the bed. She has been a part of this senior choir at our church for the last 10 years; they practice every Wednesday morning. When she could no longer drive herself to practice, I drove her. Even when she took chemo, we’d work that around her choir practice. Today, she couldn’t get to practice, so the choir came to her. They are all around her bed; they brought music, and they have a keyboard; she’s sitting up singing with them.”

Tears came to my eyes as I went back to Linda’s office. Later in the morning as the choir was leaving the building, I was in the front entry way as they loaded the bus. I was thanking each person for coming and saying what a wonderful gift their music had been for all of us.

A little lady grabbed my hand and said to me, “you know, my husband died here 3 years ago; I just couldn’t think about coming back and almost didn’t get on that bus today. I’m so glad I did; I’d forgotten what a peaceful, special place this hospice is. I’ll be back now that I know I can. And you tell that lady to ask us to come back; we’d love to come and sing anytime.”

The patient died before the next Wednesday’s choir practice, and the bus of choir members travelled to her funeral to sing.

Doris Nelms
Volunteer Coordinator
PruittHealth Hospice of Atlanta
“You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”

Dame Cicely Saunders
A Guide to Hospice Appropriateness

A doctor must write a medical order for hospice services before a patient can be admitted. When a person faces a terminal illness, he or she deserves to live the remainder of life fully, comfortably, and with dignity. Hospice care is a holistic approach that treats the physical, psychosocial, and spiritual needs of the patient and family as the end of life nears. Palliative care (comfort measures) includes:

- Pain control and symptom management
- Financial and emotional support for patient and family
- Spiritual care
- Companionship and respite care
- Bereavement services

Identifying factors that may lead to hospice diagnosis:

- Confined to bed or chair
- Weight loss of more than 10% in 3-6 months
- Increased skin breakdown
- Increased hospitalizations
- Increased pain or pain difficult to manage
- Unresponsiveness to verbal stimuli
- Assistance needed with daily living
- Swallowing difficulty
- Incontinence
- Required oxygen
- Shortness of breath
- Progressive cough
- Decreased physical coordination and balance
- Recurrent infections

A potential patient does not have to exhibit every symptom listed above, nor would he or she necessarily exhibit only one symptom. If someone you know appears to be appropriate for hospice services, PruittHealth Hospice can assist you with the evaluation process.

Hospice Diseases

When you think of a life-limiting illness, cancer is usually the first thought; however, hospice care is appropriate for any condition that has life-ending limitations. The following overview about hospice diseases other than cancer is designed to educate about some of the symptoms that you may encounter related to a patient’s diagnosis.

Cerebrovascular Accident (CVA)

Stroke continues to be the fourth leading cause of death in the United States. The two main classifications of CVA are Ischemic and Hemorrhagic strokes.

Advanced stage symptoms are:

- Comatose
- Extremities are flaccid (lifeless)
- Unresponsive to noxious stimuli
- Pupil size is unequal or fixed or sluggish
- Respirations may be deep, irregular, or intermittent
- Gag and swallow reflex impaired
- Dementia

Alzheimer’s Disease and Related Disorders

Dementia is a symptom of many diseases including Alzheimer’s Disease. Dementia involves progressive loss of mental skill, intellect and memory which impair activities of daily living. The basic process accounting for symptoms is the permanent loss of neurons. Often, the cause of death with advanced progressive dementia is infection. As the severity of the dementia increases, the chance of developing a life threatening infection increase.

Advanced stage symptoms are:

- Dependent on ADLs (Activities for Daily Living)
- Severely impaired expressive and receptive communication
- Inability to walk, stand, maintain sitting posture with head and neck control.
- Muscle rigidity and de-conditioning which leads to contractures
THE DIAGNOSIS

HIV/AIDS
Acquired Immune Deficiency Syndrome (AIDS) and its agent, Human Immunodeficiency Virus (HIV).
Advanced Stage symptoms are:
• Diarrhea
• Neuropathic Pain
• Dehydration
• Nausea and vomiting
• Delirium and dementia
• Respiratory problems
• Depression, anxiety, and Lazarus syndrome
• Fever
• Skin disorders
• Weight loss
• Urine incontinent

Heart Disease
Heart Disease is the number one cause of death in the U.S. As the heart works slower, other organs are affected by this change of pace. There are several diagnoses that may be related to heart failure: heart attack, coronary heart disease, high blood pressure (hypertension), valve disease, thyroid disease, kidney disease, diabetes or heart defects present at birth all cause heart failure.
Advanced heart failure is characterized by:
• Fatigue or weakness
• Congested lungs
• Dyspnea (breathlessness)
• Edema or fluid retention

All aspects of heart failure cause discomfort and require limited activity. Advanced Heart Failure may affect every aspect of a person’s life: physical, emotional, social, and spiritual.

Liver Disease
The liver is the largest organ in the body and performs more than 400 functions. At rest, the liver accepts a blood supply of approximately 1300 cc every minute.
Liver failure is caused by:
• Hepatitis B
• Hepatitis C
• Cirrhosis

Advanced Stage Liver failure symptoms:
• Ascites
• Hypoxemia
• Agitation, hallucinations
• Jaundice
• Bleeding of large veins
• Malaise or fatigue
• Cyanosis
• Nausea and vomiting
• Dyspnea
• Pain
• Fever and septicemia
• Pruritis (chronic fatigue)
• Skin changes
• Weight loss/wasting

Multiple Sclerosis (MS)
Multiple Sclerosis is a chronic, progressive, and degenerative disease that affects the conduction pathways of the central nervous system. MS presents a multitude of symptoms, and its course is marked by periods of exacerbations and remission with the severity and duration increasing as the disease progresses.
Advanced disease, the late stage symptoms:
• Bedridden
• Incontinence
• Painful spasms of lower extremities
• Recurrent febrile episodes from infections

Neurological Disease
Amyotrophic Lateral Sclerosis (ALS)
ALS (also known as Lou Gehrig’s disease) is a progressive degenerative disease affecting motor neurons in the spinal cord, brain stem, and motor cortex of the brain. The course of the disease is such that the average life span from onset of symptoms to death is about 3 years. Early ALS signs include:

- Weakness
- Wasting
- Cramping of hand muscles
- Loss of fine motor skills

Mid-stage symptoms:

- Decreased coordination of movement
- Spasticity of legs and arms
- Impaired speech
- Decline of muscle strength and bulk
- Drooling and difficulty swallowing

Advanced symptoms:

- Paralysis
- Muscles totally denervated
- Consistent discomfort from cramping
- Respiratory musculature causing death by aspiration or respiratory failure.

Pulmonary Disease

Pulmonary Disease, known as chronic obstructive pulmonary disease (COPD), is a long-term lung disease that makes breathing difficult. Because COPD develops over a period of time, it is most common in people over the age of 60. There are two types of COPD:

- Emphysema: airways are damaged
- Bronchitis: inflammation of the bronchial tubes

Smoking is the most common cause of COPD although inhaled chemical fumes or industrial dust may create lung infections which may lead to COPD.

Symptoms characterized with advanced COPD disease are:

- Abdominal breathing
- Hypoxemia (low blood oxygen)- breathlessness and suffocation feeling
- Cyanosis (bluish/purplish discoloration of skin due to lack of oxygen)
- Peripheral edema
- Distended neck veins
- Weight loss
- Electrolyte imbalance
- Wheezing with breathing in and out

Renal Disease

Kidney failure occurs when the kidneys stop working properly; there are two main categories: acute renal and chronic renal failure. In acute renal failure, the kidneys abruptly stop working but may eventually recover to normal function.

In end stage renal failure, the kidneys have no function and require dialysis treatment for the survival of the patient. Older adults with chronic diseases (kidney, liver, diabetes, heart failure, obesity and high blood pressure) are more likely to experience renal failure. Or renal failure may occur after some heart or abdominal surgery.

Advanced renal failure symptoms are:

- Edema (swelling)
- Neuropathy (damaged nerves)
- Confusion/restlessness
- Nausea and vomiting
- Painful gout
- Weakness
As I walked into the healthcare center on my first visit, I was met with loud hollering sounds. As I made my way down the hall, the sound got louder. To my surprise, they were coming from the very lady I was to visit.

I entered the room not knowing what I was going to do or say. I found myself talking to her like nothing was unusual, and she calmed down some.

Week after week I stopped by. Sometimes she would be hollering, sometimes silent, but no matter what, I would converse, and gradually I learned from little bits and pieces that her favorite color was purple, that she liked flowers, and that her daughter visited regularly.

One morning when I arrived, she was quite lucid — something I had never before experienced with her. She thanked me for coming and said she was proud of what I had been doing. She looked at me warmly when she spoke, and I left feeling elated at what had transpired.

The following week she passed on into Eternity.

Sarah Lottes
Healthcare Center & Home Patients Volunteer
PruittHealth Hospice of Atlanta
THE DIAGNOSIS

Pain Assessment and Management by Susan B. Prather RN, BC, CHPN, M.A.

What is pain and why is it so important?

It is estimated that approximately 2 million Americans live in healthcare centers and up to 80% of all long term care patients experience substantial pain. (Won, LaPane, Vallow, Schein, Morris, et al., 2004). It is thought that this high prevalence of unrelieved pain may result from under recognition which may result in under-treatment. When pain is not recognized and not correctly treated, there can be serious consequences for the quality of life for our patients.

What is pain?

As we begin to understand what pain is, it is important to understand that pain is more than just physical. Nurses and doctors are primarily focused on the physical aspects of pain and often medications are the solution. We need to understand that people experience many different types of pain that often influence the physical aspects of pain. When patients have social, emotional and spiritual concerns (family losses, financial concerns, broken relationships, serious medical conditions and spiritual issues, why me?), they often express this pain in a physical manner. Patients develop neck and shoulder pains, headaches and back pain. This pain is “real” and may need to be managed with expert help from trained social workers, counselors and chaplains. It is vital that patients in pain are approached from a coordinated multidisciplinary approach.

Definition of Pain

In 1968, Margo McCaffery defined pain as “whatever the experiencing person says it is, existing whenever the experiencing persons says it does.” This definition focuses the caregiver to listen to and believe the patient’s report of pain. Our first professional responsibility to the patient in pain is to acknowledge and believe the patient’s report. Pain is subjective and requires us to put aside our own opinions and believe the patient’s report.

Bill of Rights

The Bill of Rights for patients in pain provides a foundation for appropriate pain assessment and management of pain. These five “rights” are described below:

Patients have a right to have their pain believed.

It is important that caregivers demonstrate to the patient that we acknowledge and believe his/her report of pain, which is reflected in our body and spoken language.

Patients have a right to have their pain assessed and managed promptly.

As caregivers, we need to respond in a timely manner to our patient’s requests. It is not appropriate for a patient to wait long periods of time to receive pain medications.

Patients have a right to be treated with respect at all times.

We have a responsibility to “do the right thing” and not disrespect our patients with our attitudes, body or spoken language.

Patients have a right to have their pain anticipated and managed.

As clinicians we need to understand that procedures such as bathing, ambulation, transfers and dressing changes may cause pain, and patients may need to receive pain medication prior to
these procedures to diminish or eliminate pain. It is essential that we plan for these events and appropriately manage this “incident pain.”

Patients have a right to participate in their pain management.

Patients and families have a right to understand about the proposed plan of care and need to participate in the planning of that care. Belief and participation in the plan will always produce more positive results.

**Unrecognized Pain**

Sometimes, we expect a patient in pain to act in a particular way. As healthcare providers, we have been taught to look for indicators for pain such as grimacing, moaning and groaning. Many of our older patients may develop impaired cognition, and the demonstration of pain may look somewhat different. We need to consider behaviors such as aggression, biting, hitting, resisting care, yelling, and fighting as possible and potential indicators of pain. Patients may not always act as we think they should. In older patients who are cognitively impaired, we will need to first consider their diagnoses as possible indicators for pain.

**Un-relieved Pain**

It is important to treat the right type of pain with the right medication. When we don’t interpret each type of pain that the patient may be experiencing, we often have the potential to only manage one type of pain and may miss another type of pain. This may lead to poor pain management and result in increasing medications that may not be necessary. Very often our older patients experience combinations of pain and require multiple or combinations of medications.

**Under-treated Pain**

Sometimes pain is not appropriately treated because of concerns about dosages of medications. It is always appropriate to treat patients with the smallest number of medications and the least dosage possible. Often when patients have chronic pain issues and have been on medications for long periods of time, they will develop a tolerance to either the medication or the dose. When patients continue to need larger doses of medication to appropriately treat their pain, this is often misinterpreted and the patient may be under-treated.

**Myths of Pain and its management:**

1. **Lack of physical evidence**

   Many healthcare providers would prefer a “laboratory test” or some tangible evidence that a patient “really” has pain. Clearly the cause of pain cannot always be determined but not finding the cause should not lead us to ignore or deny the patient’s report of pain. Pain is subjective and needs to be acknowledged by the healthcare provider.

2. **Concern that analgesia will mask diagnostic information**

   The American Pain Society (1992) states that “In cases in which the cause of acute pain is uncertain, establishing a diagnosis is a priority, but symptomatic treatment of pain should be given while the investigation is proceeding.”

3. **Belief that non-cancer pain is not as painful as cancer pain**

   Studies have indicated that inadequate pain management is more likely when pain is NOT attributed to cancer. There is often a disregard of pain in patients that have “chronic” pain issues, i.e. arthritis and back pain. One way to address this issue may be to ask, “why are we more willing to treat a dying patient in pain...
than a patient who may have many more years to live – in pain?"

4. Implication that anxiety or depression is the cause

When the cause of pain is unknown or the degree of pain seems inappropriate, healthcare providers often attribute the pain to the patient’s emotional state and not appropriately treat the pain. Sometimes statements as “the pain is all in his/her head” are made which can lead to inadequate pain management. Often, anxiety and depression are a result of a patient not receiving appropriate and adequate pain assessment and management.

What is Addiction?

Several studies have indicated that “addiction” as a result of using opioids for pain relief occurs in less than 1% of patients. The disease of addiction is complex, multicausal and occurs over time. Opioid addiction is a psychological dependence. It is a “pattern of compulsive drug use characterized by continued craving for an opioid and the need to use the opioid for effects other than pain relief.” (American Pain Society, 1992) Addiction usually has three features, loss of control over drug use, compulsive drug use and continued use despite harm.

If a patient takes pain medication for pain management, this is NOT addiction, regardless of dose or length of time.

What is Pseudoaddiction?

This condition is a pattern of “drug seeking behaviors” in pain patients that are receiving inadequate pain management. Behaviors indicative of uncontrolled pain or fear of uncontrolled pain are often misinterpreted as addiction. These behaviors may include, “clock-watching,” demanding behavior and manipulation.

What is Physical Dependence?

This is a physiologic phenomenon that manifests as the development of withdrawal symptoms after an abrupt discontinuation of opioids. Physical dependence indicates neither the presence nor absence of addiction. When opioids are significantly reduced or withdrawn they should be slowly weaned.
What is Tolerance?
Tolerance is a predictable physiologic response characterized by the decreasing effects of a drug and the subsequent need for a higher dose or a change in medication to maintain the effect. This should not be confused with addiction. Patients and families often need to be educated about this phenomenon to ensure compliance with medication regimens.

Consequences of Un-assessed and Un-managed pain

Physical Consequences:
When patients are not adequately assessed or managed for their pain, they often suffer physical consequences that may include:
- Decreased activity
- Increased fatigue
- Increased falls
- Poor appetite – weight loss
- Nausea
- Altered sleep patterns
- Altered immune system – more susceptible to infections

Psychological Consequences:
- Anxiety
- Depression
- Anger/agitation
- Fear
- Poor compliance

Social Consequences:
- Diminished social relationships
- Financial concerns
- Issues with sexuality

Spiritual Consequences:
- Purpose-why me?
- Religious challenge
- Increased emotional suffering

Metabolic Consequences:
- Increased ACTH, cortisol, ADH, epinephrine levels
- Hypercoagulation
- Increase myocardial oxygen consumption
- Alelectasis
- Fluid overload
- Decreased GI motility

<table>
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<th>0</th>
<th>1.0</th>
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<th>Score</th>
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<td><strong>Breathing</strong></td>
<td>Normal</td>
<td>Occ. labored hyperventilation</td>
<td>Noisy labored Hyperventilation Cheyne-Stokes</td>
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<tr>
<td><strong>Negative Vocalization</strong></td>
<td>None</td>
<td>Occ. moan or groan. Low level speech with negative quality.</td>
<td>Repeated troubled calling out, loud moaning or groaning, crying</td>
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</tr>
<tr>
<td><strong>Facial Expression</strong></td>
<td>Smiling or inexpressive</td>
<td>Sad, frightened Frowning</td>
<td>Facial grimacing</td>
<td></td>
</tr>
<tr>
<td><strong>Body Language</strong></td>
<td>Relaxed</td>
<td>Tense, rocking, distressed pacing, guarding, fidgeting, rubbing, irritable</td>
<td>Rigid, biting, fists clenched, pulling/pushing away, striking out</td>
<td></td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>No need to console</td>
<td>Distracted or reassured by touch</td>
<td>Unable to console, distract, or reassure</td>
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</tr>
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TOTAL:
All of these consequences from un-assessed and un-managed pain can significantly add to the gravity of an already medically compromised patient.

**Pain Assessment Scales**

To assist the staff in the pain management process, sets of laminated cards with assessment tools are available. These assessment tools include numeric scale, color scale, faces scale, non-cognitive scale, descriptive words for pain, common pain diagnoses, and suggestions for pain management. These tools are to assist the patient in participating in his/her pain assessment and management.

It is important to use the same scale for all assessments in any particular patient. Listening carefully to the patient and believing his/her report of pain will provide the most accurate assessment of his/her pain. The various pain scales should be explained to the patient, and the patient should be assisted in choosing a scale that he/she is comfortable utilizing. The patient’s subjective report is the most accurate assessment of pain.

**Non-cognitive scale (see chart below)**

This scale should be utilized only when the patient is unable to report his/her own pain level. The ability to report pain may be compromised due to impaired cognitive function. This may be seen in various forms of dementia and Alzheimer’s disease.

At least once each shift, the nursing staff is required to ask the patient if he/she is having any pain. Remember that a patient may have a different interpretation of words, so it is important that a variety of words be used to ask about pain. An example might be to ask if the patient is hurting, or sore, or uncomfortable or aching instead of just using the word “pain.”

The shift pain assessment should be documented in the MAR (Medication Administration Record). This documentation should include the numeric rating of the pain either subjectively (the patient’s report) or objectively (the nurse assessment using the non-cognitive scale) and the nurse’s initials.

In addition to asking about the intensity of pain, it is important to also assess for the quality of the pain. Descriptive words that may be presented to the patient might be:

- Aching
- Deep
- Cramping
- Sharp
- Stabbing
- Shooting
- Pressure
- Throbbing
- Squeezing
- Dull
- Tingling
- Burning
- Radiating
**Frequently Asked Questions**

**What symptoms can I expect?**
Changes in body temperature, skin color, breathing patterns, level of consciousness with confusion, difficulty in swallowing.

**Will all of these occur at the same time?**
No. Not all of these symptoms will appear at the same time, and some may never appear.

**Patient seems so restless. Does this mean there is new pain?**
Probably not. Restlessness or picking at bed linen usually reflects a decrease in oxygen circulation to the brain and a change in metabolism.

**How will family/caregiver manage if he can’t control his bowel or bladder?**
Incontinence (loss of control) is usually not a problem until death is imminent. There may be a significant decrease in the amount of urine and stool produced. The sphincter muscles will start to relax, and the patient will be less aware of the feeling of elimination.

**What does the “rattle” mean?**
Secretions in the throat may become more profuse, but the patient’s weakness prevents coughing effectively. This noise is distressing to hear but does not indicate pain. Elevating the head of the bed and providing increased humidity will make breathing easier. Positioning the patient on his or her side may help lessen the rattle.

**Sometimes the breathing just stops for a while. Is this a final sign?**
You may notice an irregular breathing pattern while the patient sleeps. There may be a 10 - 30 second lapse between breaths (apnea which is common and indicates a decrease in circulation and a build-up of waste products). It may last for days or even weeks.

**Does the confusion come from the drugs?**
Confusion and disorientation reflect a slowing of the neurological system. Allow the patient to verbalize; do not correct or argue with his or her perception.

**How would I know if death has occurred?**
Signs of death include: no breathing, no heartbeat, incontinence (loss of bowel or bladder control), eyelids slightly open with eyes fixed, and jaws relaxed and slightly open.

**Emotional and Physical Changes in a Hospice Patient**

Withdrawal from:
- Social activities
- Family members, neighbors or church friends
- Favorite hobbies, reading, or TV programs

Changes in sleeping and eating patterns:
- Decreased food interest
- Loss of appetite; taking liquids less often
- Increased sleeping
- Less communication and conversation

Physical Body Changes Of a Dying Patient:
- Fluctuations of body temperature
- Changed blood pressure, up or down
- Blotchy, purplish or bluish skin color
- Irregularity in breathing patterns; congestion
- Decreased level of consciousness and/or responsiveness
- Inability to swallow
- Restlessness or semi-consciousness
- Inability to respond: hearing and/or visual
- Urinary and bowel changes

Summary:
- Withdrawal from people; may not want visitors
- Decreased food and fluid intake; not interested in eating or drinking

**What should I do in an emergency?**
Contact your PruittHealth Hospice office and Volunteer Coordinator immediately.
THE DIAGNOSIS

- Increased sleeping
- Decreased communication
- Disorientation; agitation; confusion
- Decreased blood pressure
- Respiration and breathing irregularities
- Increased congestion
- Fluctuation of temperature
- Fluctuation of energy levels
- Mottling of skin...blue, purplish color of skin, blotchy
- Decreased urine and/or stools
- Restlessness or no activity
- Weakened pulse

Signs of Approaching Death

Each death will be as unique as each patient. When you spend time with hospice patients, you may recognize some of these signs or see a pattern of change:

- Never assume you know what stage the patient is in
- Never share your thoughts about stages with the family or caregiver

If you have questions or concerns, talk with your Volunteer Coordinator.

Remember, you are not clinically trained.

Suggestions for Care and Comfort Measures

- Use warm, light-weight blankets (not electric), ask if the patient is cold and would like something added to the bed or chair.
- Always assume that the patient hears and understands everything said.
- Fragrances (perfumes and lotions) should be avoided
- Touch the person as you speak because it helps him/her orient towards you, and it offers emotional security that you are present; remember to ask permission before touching.
- Speak calmly with a soothing voice to a confused person; remember, some senses become more acute for some patients.
- Touch or move the body very carefully because discolored skin is fragile; always ask permission first.
- Offer ice chips, sips through a straw or a cool moist cloth to relieve dehydration; the patient may not want food or fluids; always ask patient what he/she prefers.
- Honor the patient’s requests and needs. Each death will be as unique as each patient. As you become more experienced as a hospice volunteer, you may recognize some of these signs or see a pattern of change.
  - Never assume that you know what stage the patient is in
  - Never share your thoughts about stages with the family or caregiver
- Help to create a soothing environment by eliminating loud noises and using safe lighting
- Remind the patient who is speaking and what you are going to do
- If you have questions or concerns, contact your Volunteer Coordinator. REMEMBER: you are not clinically trained.
There are times in life when the way seems long and it’s hard to understand. Even the visits to the dear Hospice patients seem mundane and pointless, especially when there is one patient who doesn’t seem to respond to your visits at all. You have read to the patient...at the daughter’s request...patient usually has her eyes closed and doesn’t acknowledge your presence. You go week after week and leave each time with heavy heart.

You have decided not to “waste your time and hers,” and when you tell your Volunteer Coordinator that you don’t think you should be visiting this patient, she urges you to try one more time.

Today, as you enter the room, eyes open and follow your movements.

On a whim, you decide to read a little aloud.

Was that a tear in the corner of an eye?

After a while, the eyes close and the head turns toward the wall. I take that as my cue that it is time to depart. I say my goodbyes, and as I go around the bed to leave a Volunteer card on the nightstand, her eyes are once again following me.

There is joy in my heart as I hold on to the hope that perhaps the visit was not in vain. And I feel a refreshed spirit as I thank God for never giving up on me and a renewed dedication to not give up on others. I will come back again...I will not let my perception of “lack of response” trick me into thinking.....my presence doesn’t make a difference.

Today...I know that I was watched, listened to...responded to by my patient.
What does a flower mean to you? A flower may lift your spirits because it smells nice, or looks pretty, or maybe someone special gave you the flower because it shows their love and gratitude. I have enjoyed our flower program at Peachtree Christian Hospice during my tenure here. I feel that it is a nice little extra that we offer; a piece of normalcy in an unfamiliar place for our families and patients. A few weeks ago, I spoke to a friend of a former patient, and during our conversation, she explained how the flowers helped her process her friend’s time at Peachtree Christian Hospice.

The patient had a rapid decline. Just a few weeks before, she had been working and involved in her community. Her friend described the patient as a beautiful spirit—so full of life and love. As she sat with her friend, she wondered how someone so genuine could be so alive one week and so helpless the next. It just did not seem fair or right to her. As she contemplated this question, she noticed the bouquet of flowers that a volunteer had just delivered, and then it struck her. These flowers are so beautiful today, but they will not be here next week. They too were like her friend, beautiful and purposeful, but a life not long enough.

I do not think that we will ever know the full extent our actions have on other people. I personally never thought of flowers in this light before, but what an impact they had on our patient’s friend! The kind donation of flowers and the gift of time to arrange them for the patient helped create a profound moment of understanding for someone.

Thank you to all of our volunteers, supporters, and staff for each moment you create for others; you may never know the impact you had in its foundation.

Natalie McNeal
Administrator, Peachtree Christian Hospice
PruittHealth Hospice
“Let us not underestimate how hard it is to listen and to be compassionate. Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely, and broken. But this is not our spontaneous response to suffering. What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant people, we want to earn our bread by making a real contribution. This means first and foremost doing something to show that our presence makes a difference. And so we ignore our greatest gift, which is our ability to be there, to listen, and to enter into solidarity with those who suffer.”

Henri Nouwen
Culture and Rituals

Culture is defined as a shared set of values and beliefs, rituals and customs, language, expectations, or behavior.

Rituals are defined as patterns of expected actions or words. All human experiences create rituals in order to limit realities that are too painful to cope with.

The dying process is a vulnerable time for patients and their families, so it is important to understand that each family’s needs, values, traditions, and rituals in relation to death and grief are as unique as each patient and family member. Accepting and understanding these differences helps us from inadvertently upsetting the patient or family member at a time when the emotional state is often fragile.

Generally, it is not possible to know a patient and family's personal preferences related to faith or beliefs without asking. Hospice caregivers must tread lightly in asking these types of questions. Remember every hospice office has a skilled chaplain on staff who is trained in end-of-life issues. If you have these types of discussions with your patient or caregiver, please share this information with your Volunteer Coordinator, so that information can be shared with the IDG team.

Self-awareness helps us to remain free from judgment when caring for others whose beliefs and customs are different than our own. All of our personal experiences and values impact our perceptions and feelings about cultural differences. Before we serve others, especially others who think, believe, and worship differently than we do, it is essential to invest time and effort to gain insight about ourselves and our responses to death that are related to:

- Past experiences
- Family traditions
- Religious or spiritual beliefs
- Heritage

Spiritual Diversity

With respect and dignity, honoring the patient’s spiritual practice and/or religious belief, individual choice and self-determination are all fundamental principles of ethical hospice care.

Religious traditions speak to the way that we live our lives and the way that we die. The individual response to any particular religious tradition can be as diverse as the religion. Because a patient expresses a religious connection, do not assume that he/she subscribes to all the tenets of that tradition.

For the hospice volunteer, a desire to be with the patient and to learn from him or her will offer the greatest support for this diversity whether spiritual or cultural.

Spiritual Issues

Spiritual concerns of the dying patient vary in depth and scope depending on a number of factors. Relationship with a divine, higher power and relationships with other people often determine a patient’s sense of spiritual well-being. Spiritual issues often seen during hospice care:

- Survival concerns for family
- “How will they do without me?” “Will they be OK?”
- Reconciliation with religious history and practice
- Unresolved conflicts
- Closure with God, family, friends, self
- Meaning of life (past, present and future)
- Relationship with family and religious community
- Ritual support & care (e.g. scripture, prayer, Eucharist, sacrament of sick)
- Abandonment by God
- Fear of the unknown
- Anxiety about after-life
- Hope versus despair
- Guilt
- Anger
The Bereavement Process

• Assurance of salvation
• Spiritual doubt
• Questioning about past spiritual beliefs (reconciliation thereof)
• Questioning about the after life, 'the other side'

Because each patient is an individual, hospice care is customized to meet his/her unique spiritual needs. Because the hospice chaplain is trained to address a variety of end-of-life spiritual issues, communicate your questions or concerns directly with him or her.

For a comprehensive overview of different faiths and spiritual practices visit www.beliefnet.com.

Grief and Loss

Hospice care recognizes death as a natural part of the human experience. Our adaptation to this experience, our normal and natural response to death and dying is the process of bereavement. Coping in response to that loss can vary.

The patient’s grief response to the terminal illness and the pending loss of life challenges the psyche, the spirit, the relationships, the self-perception and often much more.

Death never happens in isolation.

When the individual dies, a community is affected. Family members and caregivers are dramatically impacted, as are extended family members, neighbors, church friends, work friends, etc. All of these extended family members are defined as part of the family support system. In order for a hospice team to provide holistic bereavement care and support, all lives connected by the dying event are a concern of the hospice team, and efforts are made to include as many of these connections into the dying and bereavement process.

Through bereavement services, the patient’s needs are supported which also benefits the family system as well. Even in those circumstances where there is little or no family, there is often a healthcare center that has taken on some of the roles of family members. And like those in the family support system, these healthcare individuals may also manifest their own bereavement needs and concerns.

The Bereavement Assessment and Care Plan

The bereavement assessment actually begins with each discipline’s initial assessment. On admission the nurse identifies bereavement concerns on the initial POC (Plan of Care). On-going assessment is the task of the interdisciplinary team to identify the patient and family needs related to bereavement, grief, and loss. If issues are identified, it is recommended that a grief care plan is initiated.

The hospice team assesses the patient and family within 5 days. On-going assessment is the task of the interdisciplinary team to identify the patient and family needs related to bereavement, grief and loss throughout the patient’s hospice stay.

The following items provide framework to talk about the bereavement concerns:

• Ineffective coping skills
• Multiple losses
• Lack of support systems
• Unfinished business

Bereavement services are extended from the patient’s admission into hospice care through the bereavement time with the survivor’s concerns which is a minimum of 13 months beyond the death of the hospice patient.
Factors that Impact the Grieving Process

The grieving process is an individualized, personal experience. As bereaved experience the work of grief, individual differences are displayed. Several factors determine an individual’s reaction to grief and bereavement; these factors are interrelated and influence the impact of the death on the survivor.

C.M. Parks in Bereavement: Studies of Grief in Adult Life discusses several factors that affect the grieving process. All of these factors affect how a bereaved copes with death and moves through the grief process and how he or she changes life after the death of a loved one. 40

Relationship to the deceased

Relationships to the deceased affect the grieving process; for example, spouses may have lost a life-long love and companion. The age of the deceased also influences the grief reaction. The deaths of elderly people, such as grandparents, are often expected and easier to bear; however, the loss of a young child, exacerbates the grief reaction, especially for parents and siblings.

Quality of relationship

The quality of the relationship between the bereaved and the deceased prior to the death may affect the passage through the grief process. The degree of attachment, security, and conflict before the death can create difficulties in the grieving process. If one is emotionally attached to or financially dependent upon the deceased, the grief reaction may be more intense. If there was conflict in the relationship, the bereaved may experience increased feelings of guilt.

Type of death

The type of death and the manner of death affects the grief process. Accidental and unexpected deaths give bereaved no time to anticipate and prepare for the loss.

(Anticipatory grief often allows the grieving process to be less intense). When a bereaved has witnessed a loved one die in great physical pain, this trauma can complicate his or her grief.

Experiences and history of losses

Prior experiences with death may affect the reactions to the loss. For example, if a bereaved had a bad experience with death at another time in his or her life, he or she may have more difficulty with grief resolution. If he or she has experienced multiple recent losses, including job loss, divorce or separation, the grieving process may become overwhelming because there has not been sufficient time to resolve other feelings of grief. Cumulative loss is an issue that affects all grief responses and often prolongs the grieving process.

Other stressors

Other stressors, such as financial difficulties, the need to care for other frail or ill family members, difficulties with children, and conflicting relationships, affect the grieving process. The more stressors that are present in the lives of survivors, the more difficult the grieving process becomes, and often, lengthens the grieving process.

Myths of Grief

Myths are often a result of misunderstanding and/or societal influences. Overall, Western society has adopted a death-denying mentality. By denying death, Americans often suppress the needed expression of grief. Because we are independent and self-sufficient, we generally attempt to exert some control over loss, death, and grief by avoiding participation in the grief process and the pain that accompanies a loss.

We may avoid participation in the grief process and the pain that accompanies a loss.

Alan Wolfelt, Director of the Center for Loss and Life Transitions in Fort Collins, Colorado, debunks some myths about grief and mourning. 41

Myth #1: Grief is the same as mourning
Hospice Approach: Grief is not the same as mourning. Mourning is the outward, social expression of the loss. Each culture mourns in different ways, and cultural norms, rituals, and traditions may direct the mourning process. Members of some cultures may be very emotional and verbal in their expression of grief. Other cultures may require that mourners appear stoic and reserved. Religious and cultural beliefs may dictate how long the mourning period continues and how the bereaved “should” act and react during the bereavement period.

Grief is the emotional feeling that results from the loss. It is the “inner,” personal feelings of the survivor and cannot be directly defined or observed by others. These feelings may include anger, frustration, loneliness, sadness, guilt, regret, and an array of other feelings; all feelings are individual and personal.

Myth #2: The grief and mourning period is predictable and follows an orderly pattern and progression

Hospice Approach: Each bereaved goes through the grief and mourning period in his/her own way, with coping skills in accordance with cultural norms and in conjunction with life experiences. While there are some commonalities in the stages of grief, the responses may differ among individuals.

Myth #3: It is best to avoid grief rather than move towards it

Hospice Approach: Our society often believes that it is inappropriate to cry as a public expression of grief and that this behavior signals poor control over one’s emotions. For many but not all bereaved, tears are an expression of grief and an important component of the grief process. Crying is an appropriate expression of grief, facilitating a healthy release of emotions.

Resources

PruittHealth Hospice Foundation
http://www.pruittcares.org

Camp Cocoon – Helping Children Find Life After Loss
Every year, our PruittHealth Hospice Foundation sponsors Camp Cocoon, a camp for children ages 6-17 who have experienced the death of someone they love. Camp Cocoon is funded by donations and fundraisers and is hosted by a volunteer staff of employees and hospice volunteers.
If you are interested in learning more about this camp or volunteering with Camp Cocoon, log onto the foundation website.

Center for Loss and Life
Dr. Alan Wolfelt
http://www.centerforloss.com

Grief Counseling Resources
• AARP
• Kenneth Doka
• Hospice Foundation of America
• Center for Loss and Life
Volunteers Make a Difference

We had a patient in one of our healthcare facilities who was usually sitting up in bed when I went to see her, but she seldom responded in anyway. Her eyes were glazed; she didn’t speak and often didn’t look at you at all when you entered her room. She had been on our service for about six months, and I had never heard her say a word, even when anyone got close to her and touched her.

One day her sister and I were visiting her, and although we both talked to her, touched her; she didn’t even move or blink or acknowledge either of us. However, when our hospice volunteer, Ludora Randall, came in to see her, it was amazing to me. She knew who Ludora was and immediately began to try and talk to her. And she was trying to sing; I think she even said, “Jesus loves me.”

And Ludora said, “Oh, yes, we talk about Jesus all the time and how he loves all of us. She knows who I am.”

It was a beautiful thing to see and experience; her sister and I both were so shocked by the patient’s response to Ludora.

And it is a real testimony to Ludora, to her work, her care, and her spirituality in working with hospice patients. She was able to reach beyond the place that a family member could go and get this patient to hear her and respond to her.

Ludora Randall has been a blessing to many patients, families and staff members in the Atlanta area for years, and we’re thankful that she has served with us as a PruittHealth Hospice volunteer.

We’re so thankful for the years of service that she has given to our hospice patients, and although she’s retired from hospice volunteering, she’ll never retire from the service of helping others and doing the Lord’s work.

Alicia Andrews
Social Worker
PruittHealth Hospice of Atlanta
CHAPTER 6

The Hospice Volunteer
Hospice Volunteer Qualifications

- Desire to connect – to meet and get to know another individual
- Willingness to learn – not presuming you need to know everything about any particular religion or culture but willing to learn
- Trust in the individual patient – holding a perspective that life’s journey has given the patient resources to draw from during times of transition and challenge
- Comfortable with silence
- Ability to avoid judgment
- Gift for listening – allowing a patient to tell his/her life story or express anxiety, anger, or fear without having to respond

Volunteer Services and the Bereavement Process

As a patient nears the end of life, the need to be surrounded by acceptance and support for who he/she is and what he/she believes. Challenging what the dying patient believes may even complicate his/her dying process. Families who have disagreements about religion or salvation add further division to already stressed relationships, and often these types of discussions complicate and extend the grieving and healing process for survivors.

Respect for the belief system of others is an inherent part of the hospice philosophy. By becoming a hospice volunteer, you are honoring the patient’s and family’s rights to their own beliefs, whatever those beliefs are. Because the patient has the right to follow whatever cultural traditions and spiritual beliefs that they want, the hospice staff must be aware of these differences and honor the patient’s choices. AND the patient has the right to refuse any and all spiritual support, so the staff and volunteer should know this information in advance of a visit.

Your Own Grief Work

Each of us who have experienced a loss are never the same person that we were before that loss; grief, grieving changes us. And many grief counselors believe that we never recover from that loss. The loss stays with us and affects who we are and the decisions that we make from that point forward. Because of your own loss experience, as a volunteer, it is important that you have completed your own grief work before volunteering to work with others in the grieving process. This means that you have defined your own grief history. Hopefully, you understand how you integrated those losses into your own life and how those losses have changed you.

Since grief is an individualized experience, only you will know if you are ready to become a hospice volunteer. Volunteers who have experienced the death of a loved one in the last year are asked to wait before working directly with patients.

Because most hospice volunteers are persons of faith and find meaning in their volunteer service, a particular belief system may be the reason for becoming a volunteer. Some volunteers believe it is their responsibility to share their faith when they volunteer, which may be appropriate for religious sponsored organizations but not for hospice work. If you can not honor this guideline of not sharing your faith belief, you may want to find another way to serve hospice patients without having direct contact with them.

If you would like to pray for your patient or their family, and they are of the same faith or a different faith, rather than assuming that it is okay, always ask permission.

“May I pray with you?”

In most cases, the answer will be yes. Most patients do not need to know the details of your faith tradition to be comforted by the fact that you will pray for them out of that faith tradition.
When a patient or family member has no faith tradition (they are agnostic or atheist), usually they are not looking to get into discussions about God, please don’t initiate or force a conversation regarding faith concerns. Remember this is good etiquette for whatever the person believes, spiritually or culturally.

As a volunteer, it is helpful for your conversations to focus on what has brought meaning and purpose to the patient’s life and allow him/her to tell you stories and life experiences, which may or may not include faith beliefs or expectations.

Remember, you are the listener and the guide for conversation about the patient and his/her life; it is a gift to the patient if you ask questions and let the patient provide the answers.

One important volunteer responsibility is to report to your Volunteer Coordinator any conversations or questions that have been asked by the patient that relates to spiritual issues.

All of us are naturally programmed to fix things, to offer advice, to have answers, and it is very difficult to NOT give personal beliefs and thoughts. It is an on-going life practice and art to listen, to be present, to be quiet, and to offer no solution or answers.

Do not try to resolve these issues or concerns (remember a hospice team has trained chaplains on staff); your volunteer role is to listen and be present with the patient and family and to record any activity or conversation for other team members.

**On-Going Contact**

Bereavement work is enhanced when hospice team members who served the patient and the family continue contact after the patient’s death. It can be as simple as making a call, sending a card, or stopping by for a visit. The emphasis is on continued connection.

Follow-up with family members of patients with phone calls, personal notes or visits to continue the connection.

Volunteers can assist the hospice staff in hosting a memorial service and inviting the patient’s family members.

**Communication**

Hospice Volunteers have the opportunity to establish rapport and to create positive, meaningful relationships with those we serve through empathy and authenticity. When we communicate to patients and families that we want to understand their hopes and concerns, we gain their trust and confidence.

Empathy is the ability to accurately perceive a person’s feelings and the ability to communicate understanding of these feelings.

Authenticity is the sharing of self by relating in a natural, sincere, spontaneous, open, and genuine manner.

**Active Listening**

Utilizing active listening skills can assist in establishing rapport and understanding of the needs of your hospice patient and family.

Active Listening is defined as:

- Taking in information while remaining non-judgmental and empathetic
- Acknowledging the speaker in a way that invites the communication to continue

By using active listening, we allow patients to express feelings, and we send the message that what they are saying is important and valued. When we listen to our patients and families, we learn valuable information about their needs.

You may be tempted to interrupt patients and families during your visits and to control the content and direction of the conversations.

Try not do that; your role is to listen and encourage them to talk.
Attending Skills

Research indicates that 85% of all communication is non-verbal; therefore, attending skills require you to give your physical attention to another person. Attentive non-verbal communication indicates that you are paying attention to the patient who is talking and that you are interested in what he or she has to say.

The following techniques are effective attending skills:

**Body Posture**
- Inclining one’s body toward the patient
- Facing the patient squarely
- Maintaining an open position not crossing the arms or leg
- Keeping an appropriate distance

**Body Motion**
- Listeners who remain too still may be viewed as controlled, cold, or aloof
- Listeners who are more active (not in a nervous, fitful way) are perceived as friendly, warm, and casual
- Avoid distracting motions and gestures such as drumming fingers, swinging a crossed leg up and down, fiddling with pens, or jangling keys
- Try to find a comfortable medium

**Direct Eye Contact**
- Says you are listening
- Allows the speaker to appraise your receptiveness to him or her and his or her message
- Lack of eye contact may be perceived as lack of interest

Create a Comfortable Environment
- Minimize distractions to give the patient your full attention
- Remove sizeable physical barriers to put the speaker at ease and better assess non-verbal communication

Following Skills

Following skills provide a non-coercive invitation to talk, particularly if you sense that the patient needs encouragement. Invite conversation with your patients and families but do not demand it.

**Door Openers**
A description of the patient’s body language
Example: “You seem a little down today.”

**An invitation to talk**
Example: “Is there something on your mind that you’d like to talk about?”

Allow silence which gives the patient time to decide whether to talk or what to say. Use attending skills (eye contact and posture) that communicates your interest and concern.

**Minimal Encouragers**
These responses do not imply either agreement or disagreement with what is said but allows the patient to know that he/she has been heard. Simple responses that encourage the speaker to tell his story.

Examples:
- Oh? I see. Right. Really?
- Tell me more. And?
- Go on.
- For instance…, mm-hmm. Sure.

**Infrequent Questions**
Excessive or closed-ended (yes/no) questions can become barriers to communication.
- Ask only one question at a time
- Use minimal encouragers to further conversation
- Be comfortable with periods of silence

**Attentive Silence**
Allowing silence gives the patient time to think about what he/she wants to say, proceed at his/her own pace, and deal with ambivalence about sharing.
Use silence to:
- Attend to the speaker.
• Observe the speaker.
• Think about what is being communicated.

Reflecting Skills

The art of good listening involves the ability to respond reflectively. In a reflective response, the listener restates the feeling and/or content that the patient said in a way that demonstrates understanding and acceptance.

Paraphrasing

• A concise response to the speaker which restates the other person’s message in the listener’s own words.
• Be careful not to “parrot” the patient by repeating the same words they used.
• Focus on the content of the message.
• Deal with facts and ideas rather than emotions.

Example: Patient’s son: “I don’t know if I can take care of Mom at home anymore. It’s becoming too much for my wife and I to handle, especially with two preschoolers at home. But I feel terrible about putting her in a healthcare center. She’s always hated the thought of that.”

Hospice response: “You’re facing a tough decision right now. You want to care for your Mom at home, but you and your wife are reaching a limit about the level of care you can provide while balancing other family responsibilities. You have to do what is best for everyone, not just for your Mother as hard as that is to do.”

Reflecting Feeling

Reflecting feelings help the patient to understand his or her own emotions and move toward a solution of the problem.

• Mirroring back to the patient with clear statements the emotions that he or she is communicating
• Focusing on the content of the message

Example: Patient’s son: “I don’t know if I can take care of Mom at home anymore. It’s becoming too much for my wife and I to handle, especially with two preschoolers at home. But I would feel terrible about putting her in a healthcare center. She’s always hated the thought of that.”

Hospice response: “Sounds like you’re feeling guilty about the idea of placing your mother in a healthcare center.”

Reflecting Meaning

Joining feelings and facts in one clear response.

• “You feel...because....”
• Try to use natural language.

Example: Patient’s son: “I don’t know if I can take care of Mom at home anymore. It’s becoming too much for my wife and I to handle, especially with two preschoolers at home. But I feel terrible about putting her in a healthcare center. She’s always hated the thought of that.”

Hospice response: “It seems to me that you feel guilty about considering healthcare center placement because your Mother has always been opposed to that. I know that it’s difficult to wrestle with this decision and come up with a solution that meets the needs of both your Mother and your family.”

Hospice work is stressful, emotional work. Even the best professional caregivers find it hard to keep clear boundaries.
Guidelines for Improving Reflective Listening:

• Observe the person’s facial expression, vocal clues (rate of speech, choice of words, pitch, intonation), and non-verbal communication (posture, gestures)
• Note discrepancies between verbal and non-verbal communication. For example, a patient who yells, “I’m not angry” and hits a table with his fist sends a conflicting message
• Don’t fake understanding about what the patient or family member is saying. Be proactive about seeking clarification. Ask questions about what you do not understand
• Avoid using non-verbal communication barriers
• Vary your responses. Develop a wide range of vocabulary to help reflect feelings
• Don’t be judgmental about the person speaking
• Avoid trivializing distress or suffering

Boundaries and Taking Care of You

The hospice volunteer enters into the lives of patients which is a sacred place. The intimacy potential and the human connection make this work meaningful for all of us.

Because this work happens in a context of human relationships, most likely, it will touch your own issues at some point. While hospice work is high on the meaning scale, emotional involvement and discipline with balance are required by the volunteer and all other hospice professionals.

Beyond the dying patient, the family dynamics are another layer of the complexity of hospice care. Each family member and caregiver has his or her own reaction to the patient and the loss that death will bring; fear adds strain to all relationships. Therefore, do not take these reactions personally because these emotions are often related to fears and unknowns that have nothing to do with you at all.

Hospice work is stressful, emotional work. Even the best professional caregivers find it hard to keep clear boundaries. Working through these feelings is the responsibility of the volunteer, and you must do this before volunteering with a dying patient and family.

Being in the presence of these emotions, you will naturally feel some response which is why professional boundaries are a must. Between connection and support and codependency and enmeshment, the challenge is to keep balance and healthy response. Giving compassionate care without codependency is an on-going process.

Your first responsibility of care is to you. Every loss will remind you of other losses; grief and loss are a life-time work. As a volunteer:

• You must have sorted through your own emotions before you begin serving others and experiencing their emotions. If you have not done this important self-care work, you will find yourself remembering and reliving your own grief, and those emotions will surface in an inappropriate place or time.

• You must know and honor your own needs and create boundaries that will allow you time out, respite care, and time away from this work and the grief process; otherwise, you will experience burn-out.

Those who see hospice as a “calling” or a ministry often fair better or stay longer in this work; however, burn-out is common in all hospice professionals. A seasoned volunteer will recognize these personal challenges and find ways to balance the self-giving with the self-care taking.

Sometimes the Volunteer Coordinator may recognize these challenges before you do, trust his or her experience, expertise, and be open to
this conversation as an opportunity for professional growth.

And if you find that as much as you want to do this work, you realize that it’s not what you thought it to be, or it’s harder than you realized, or it’s just not working for you, then be the first to voice this knowledge.

Be honest and true to yourself and keep searching for that right match of your gifts and your service. Our role is to train you and help you find comfortable ways for you to serve our patients; however, if this is not the right fit for you, we wish you well as you continue your journey to find that match of gifts and service. And we affirm that journey of searching to match your gifts with the right volunteer option.

**Attachment Is Normal,**
**Grieving is Part of the Loss**

We do get close to patients which is what makes hospice volunteer work so wonderful. Sharing and caring is very satisfying; however, this caring can leave us vulnerable. Hospice patients die, and we will grieve and feel sadness with each and every loss. The challenge to the hospice volunteer is to keep a perspective on the patient’s needs and on our caregiver responsibility, while recognizing and deliberately staying within our own professional boundaries.

- Letting go is essential; you will have stories, memories, and feelings of success - but you must let go of them
- Finding satisfaction that with your time, gifts, resources, and energy, you gave what you were supposed to offer to this patient and family
- Allowing yourself time to grieve is essential if you have been close to the patient and family

The normal and natural emotional response to a loss is grief. Listed are a few of the complex responses that are a part of the bereavement process.

- Crying
- Emptiness
- Indifference
- Aimlessness
- Preoccupation
- Despair
- Sleeping too much
- Loss of sleep

Grieving is an emotional response that assists the process of healing. It can be a demanding taskmaster, but ultimately your role is to care for you.

**Self-Care with Healthy Living**

Take care of yourself in healthy ways. This is wonderful advice, but the reality is that few of us do this right all the time. It is a challenge in the midst of our busy lives to live a healthy life.

Healthy life practices. No one does them all. Remember you are in charge of you, and you are challenged to know when it’s time to take your own respite.

Healthy Life Practices:
- Eat well
- Exercise often
- Get appropriate sleep
- Take time off/out
- Develop hobbies

**Responsibility**

Self-care is on-going and dynamic because our needs are ever changing.

Celebrating life and wholeness is when we find the place to be “imperfect” humans; learning, growing and taking care of ourselves is an important part of healthcare, especially hospice work.

If you are reading this, your commitment to yourself is also a commitment to those that you serve. Your willingness to give says so much about you.
Volunteer Documentation

When volunteers are asked what motivates them to provide hospice service to others, many answers arise.

- Some express that they want to give back to a certain cause with which they have had ties
- Others want to do something meaningful like hospice services
- Often we hear our volunteers say they “want to give to someone else the gifts of service that was given to me by hospice.....”

Accurate, appropriate documentation is one of the most vital requirements for hospice volunteer work.

Documentation is required because:
1. It is proof of a patient visit, “If it isn’t documented, it didn’t happen.” It provides a paper trail, protecting you, should the visit be questioned
2. It provides the hospice team with information regarding when you visited and what happened during the visit
3. It provides the Volunteer Coordinator with information needed to calculate Cost Savings
4. It is required by state and federal regulatory agencies

Appropriate Documentation:
- All documentation must be written in black ink ONLY
- White-out is absolutely not allowed, and nothing should be scratched out. To make a correction, draw a single line through the portion to be corrected, sign and date the correction, and add corrected information. Do NOT write the words “error,” “wrong date,” “mistake,” etc.
- All entries must be signed and dated appropriately
- Time on the phone and visit time with patient and family is direct time
- Information on when you visited, where you visited, who was present, and what happened during the visit should be recorded. Volunteer notes MUST be on the chart within 5 days of the visit
- Preference is within 24 hours of the patient visit

The Volunteer Coordinator shares your visit information with other hospice team members at IDG meetings. The details of your report are important in the coordination of the patient’s care.

What Not To Report:
Remember you are not a clinical staff member. Do not include clinical commentary. Do not say the following:
- “Patient was in a coma.”
- “The nurse was an hour late giving patient his pain medication.”
- “I think the cancer must have metastasized to her brain.”

Appropriate examples:
- “Mrs. Jackson did not awaken to touch or voice.”
- “Mr. Smith stated that his leg was really hurting, so I notified the nurse.”
- “Mrs. Jones was more forgetful than she was on the last visit.”

Ways to Document Visits:

There are two ways that a volunteer can document patient visits. Volunteers can record visits through the PruittHealth website. Your Volunteer Coordinator will provide you with specific instructions. The second way is by manually describing what took place during the visit on the PruittHealth Hospice volunteer visit form.

Summary

Remember that your volunteer documentation becomes a part of the patient’s medical record.
1. Make sure that each visit, call, card, or other contact is recorded
2. Make sure that the services provided match the services that you were assigned to provide.

3. Do not include unnecessary personal commentary.

4. Do not use the documentation as a means of conferring any non-patient related information.

5. Do not include information relating to any patient other than the one you are assigned to visit.

6. If you identify a problem and document it, please call the PruittHealth Hospice office to report the problem (such as pain) immediately. If your patient is in a healthcare facility, notify a nurse immediately, then call your Volunteer Coordinator or your PruittHealth Hospice office.

7. Document your follow-up call including who you shared this information with.

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**Listening**

*by Ralph Roughton, M.D.*

*Atlanta, Georgia*

When I ask you to listen to me and you start giving advice, you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn’t feel that way, you are trampling on my feelings.

When I ask you to listen to me and you feel you have to do something to solve my problem, you have failed me, strange as that may seem.

Listen! All I asked is that you listen, not talk or do - just hear me.

Advice is cheap: 10 cents will get you both Dear Abby and Billy Graham in the same newspaper.

And I can do for myself; I’m not helpless. Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself, you contribute to my fear and inadequacy.

But, when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I can quit trying to convince you and can get about the business of understanding what’s behind this irrational feeling.

And when that’s clear, the answers are obvious and I don’t need advice.

Irrational feelings make sense when we understand what’s behind them.

Perhaps that’s why prayer works, sometimes, for some people - because God is mute, and s/he doesn’t give advice or try to fix things. “They” just listen and let you work it out for yourself.

So please listen and just hear me. And, if you want to talk, wait a minute for your turn, and I’ll listen to you.32
Grief and Loss Review

Most of us do not want to die.

The end of life is something we postpone thinking about, even discussing.

Many of us are reluctant to confront the end of our existence because of a fear of death and the process of dying.

We often avoid discussing death and dying; usually we are forced into these discussions because of an illness or an accident.

Most of us are more afraid of the death process than the actual dying. Some fears center on the event of death itself; other fears relate to the loss that death will bring...and all those affected by that loss.

Grief is life-time work for anyone who suffers a loss; you will not forget that person you loved. However, time and distance will help you be less emotional in your grief. That loss will help you be a more compassionate volunteer, but at no point, do you want your own grief to surface, or overshadow or mingle with your patient’s or family members or caregiver’s grief.

Therefore, doing your own grief work is an important aspect of hospice volunteering, and you are the only person who will know if there’s more work for you to do as you open yourself to walking with a terminally-ill patient.

As you review your grief experiences, are there unanswered questions about your fear of death and dying.

This “grief work” is to help you evaluate where you are with your previous loss... losses. As a companion to a terminally ill patient and his/her family members and caregivers, you want to be sure that you have resolved your fears related to death and dying, as well as moved through your previous grief experience to the point that it will not surface in your care-giving role.

These practices are for you only...this is not homework...this is not for anyone else to read... unless you choose to share it. We hope that this is the beginning of your on-going grief work.

What do you most fear? __________________________
______________________________
______________________________

Why? __________________________
______________________________

_ I fear death more than dying
_ I fear dying more than death
_ I fear both
_ I don’t want to think about either choice

The thing that frightens me about dying is:
_ The pain
_ Progressive deterioration and disability
_ Losing control; physically, emotionally, both
_ Losing control; job, family, friends, life
_ Being alone
_ Not knowing what is happening
_ Not being able to afford good medical care
_ Being a burden for family
_ Being alive, hooked up to machines, a vegetative state
_ CANCER especially because _______________________

Any other fears related to death or dying: ____________
______________________________
______________________________

The first death that I experienced was the death of ____________, who was ___________; I was ___ years old.

At that time I felt __________________________
______________________________
______________________________

I was most curious about __________________________
______________________________
______________________________

What frightened me the most was __________________________
______________________________
______________________________

Now when I think about death, the fears or feelings that surface are __________________________
______________________________
______________________________
The first person who was my age and died was ___________________________________________.

We were age ________________, I remember thinking ___________________________________________.

My first family member died when I was ____. This death was significant to me because _________________________________________________.

The most recent death (loss) that I have experienced was _________________________________________________.

This death was different for me because _________________________________________________.

The most traumatic death experience that I have been touched by was _________________________________________________.

At age ____, I came close to death when _________________________________________________.

I expect to live until the age ____ because _________________________________________________.

On both sides of my parents family, the average age of life is (was) _____. Mom ____ Dad ____

In the space below, draw a line that represents you and your total life span. Line can be any length.

Now draw another line of any length; a straight one with a beginning and end. Slash a mark at any point along that line that identifies where you are today in your life’s chronology.

When you compare your present age with the age that you expect to die, how much of your life have you already lived? Look at the line with the slash mark; how does the estimate of time left to live compare to your numerical answer of how long you think you will live?

Answer the following:
I was uncomfortable estimating my life span because _________________________________________________.

I was comfortable estimating my life span because _________________________________________________.

The type of death that I would least want for myself is _________________________________________________.

Because _________________________________________________.

I would like to have the type of death that _________________________________________________.

Why? _________________________________________________.

What I want my family to understand about death is _________________________________________________.

I have completed my Advance Directives, but _________________________________________________.

I have not completed my Advance Directives because _________________________________________________.

When you compare your present age with the age that you expect to die, how much of your life have you already lived? Look at the line with the slash mark; how does the estimate of time left to live compare to your numerical answer of how long you think you will live?

Answer the following:
I was uncomfortable estimating my life span because _________________________________________________.

I was comfortable estimating my life span because _________________________________________________.

The type of death that I would least want for myself is _________________________________________________.

Because _________________________________________________.

I would like to have the type of death that _________________________________________________.

Why? _________________________________________________.

What I want my family to understand about death is _________________________________________________.

I have completed my Advance Directives, but _________________________________________________.

I have not completed my Advance Directives because _________________________________________________.
have always given thought about volunteering for Hospice. My dad in New Jersey and my grandma in Florida had used their local hospices years earlier.

Teaching for 30 years didn’t leave me much time for Hospice, but in January 2011, after I had been retired for a while, I knew this was the right time. Having our Director of Nursing move in next door really gave me the push to start volunteering. After turning in lesson plans and following strict educational objectives for years, I find that it is a joy to come to the office. I usually hear someone say, “Thank you for all that you do for us.”

When I come into the office, I often think “What will be my assignments today?” As an office volunteer, logging 2-4 hours a week, I do many different jobs. I might start the day by filing patient reports, copying new documents for the nurses/CNA’s, filing DME requests for our Administrative Assistant, creating marketing booklets for our CRR, or making new admission folders for our DHS.

Another part of my hospice experience is visiting my little lady in a nursing home for an hour each week. Mrs. N has dementia. When I first met her in July 2011, she told me all about being a social worker earlier in New York City and growing up in a large family in South Carolina. We talked about her grandma’s recipe for stuffed pork chops and how to cook turnip greens successfully. She and I would sing “Blessed Assurance” and other hymns. She would elaborate about how her mama would get her and 4 of her siblings to sing in mama’s church choir. I knew music was one way to help her connect the past with the present.

As the months go by, however, Mrs. N tells me that she doesn’t sing, never has, and doesn’t want to try. She has never remembered my name, but she loves the cup of Dunkin’ Donuts coffee I bring every week. She squeezes my hand as I leave and tells me she enjoys our visits. She gives me peace and memories of my grandma; I accept her as she is.

I so look forward to our visits each week. I go home feeling that I have paid it forward.

Georgie Jackson, Volunteer
PruittHealth Hospice of Coastal Carolina
New Bern, NC
CHAPTER 7
Policies, Procedures & Safety Guidelines
HIPAA and Confidentiality

As a volunteer, you will be privileged to hear and know personal, private information about our patients and family members; therefore, it is important for you to understand PruittHealth Hospice’s privacy practices and how to protect our patient’s personal health information.

The HIPAA Privacy Rule is part of the Health Insurance Portability and Accountability Act (HIPAA) of 1999, took effect on April 14, 2003, and ensures that all personal medical information that is shared is protected while allowing the flow of health information needed to provide and promote high quality health care.

As a rule of thumb, private information that you see, hear, or say must be kept confidential and can only be used or disclosed for specific purposes related to the treatment of patients, for payment for the services received or related to the operation of the agency.

Use and Disclosure of Protected Health Information

When a patient gives personal health information to a covered entity, that information becomes Protected Health Information (PHI). The terms “use” and “disclosure” are important in understanding how employees and volunteers can appropriately protect an individual’s privacy and still get the job done.

“Use” simply refers to how confidential patient information is used within an organization to treat the patient, perform the billing function, and support the operations of the agency. Only employees and volunteers with a legitimate need to know the information in order to fulfill their job responsibilities are to access PHI.

“Disclosure” relates to how you communicate protected health information to an outside person or entity. Information may be disclosed verbally, transferred by fax, or accessed though the computer system. The receiving party must be authorized and have a need to know in order to receive the PHI. If an outside person asks for information about a patient and permission has been granted, directory information may be disclosed. Directory information includes the individual’s name, location if in an inpatient facility, or condition in general terms (good, fair, poor, critical).

Patients’ Rights

- Patients have the right to see their own protected health information. However, they do not have the right to keep or take anything from the medical record.
- Also, they have the right to request a change after they have read the medical information, but the request must be investigated to make sure it is reasonable and correct. When an individual requests to view the record, always notify the administrator or his/her designee.
- Patients have the right to restrict the use and disclosure of their PHI. For instance, they have the right to keep family members from knowing their medical conditions, if they wish.
- Patients have the right to know where their PHI goes, who sees it, and how it’s used. In other words, they have the right to request a list of when and where their confidential information was released. Exceptions to this include information disclosed for treatment, payment, or support of operations.
- Patients have the right to file a complaint if they believe their privacy rights have been violated.
- Patients have the right to receive a notice of privacy practices of the agency. The notice should describe how medical information is used and disclosed, how medical information is
accessed, and how they may obtain a copy of their medical record.

Confidentiality

Confidentiality comes from two Latin words, “con” (with) and “fides” (faith or trust). Confidentiality, then, means with trust. It is the presumption that medical information will remain private and will be used only as necessary to provide care or treatment.

Invasion of Privacy is a legal term used to describe circumstances when personal information is exposed publicly that violates a patient’s right to privacy. The patient’s chart or medical record is a legal document. It is the property of the agency. The information within the chart is protected and cannot be divulged, or repeated, except as it pertains to the care of the patient on a need-to-know basis with other healthcare professionals. All information the patient shares with staff is confidential and should not be repeated.

As a general rule, it would be a breach of confidentiality to discuss a patient’s personal information with:

- One patient to another patient
- Relatives and friends of the patient
- Patient’s visitors
- Your own relatives and friends
- Fellow workers, except when there is a need to know, for example, in an IDG meeting

HIPAA protects our fundamental right to privacy and confidentially, which means that HIPAA’s Privacy Rule is everyone’s responsibility.

Abuse and Neglect

Every year an estimated 2.1 million older Americans are victims of forms of abuse and neglect whether physical or psychological. Abuse means any intentional or grossly negligent act or series of acts or intentional or grossly negligent omission, any act that causes injury to a patient, including, but not limited to:

- Assault or battery
- Failure to provide treatment or care
- Sexual harassment of the patient

There are several forms of abuse.

- Physical abuse ranges from slapping to severe beating. When someone uses enough force to cause unnecessary pain or injury, even if the reason is to help the person, the behavior can be regarded as abusive
- Emotional abuse ranges from name calling to threatening the individual
- Sexual abuse ranges from sexual exhibition to rape. Sexual abuse can include inappropriate touching or any unwanted sexual behavior
- Neglect ranges from withholding appropriate attention from the individual to intentionally failing to meet the physical, social, or emotional needs of the individual. Neglect can include failure to provide food, water, clothing, medications, or failure to manage the individual’s money appropriately

There are several signs of possible abuse/neglect. Red flags which indicate abuse include:

- Failure to seek health care despite symptoms of obvious disease
- Inappropriate choices on the part of the caregiver
- Malnourishment or dehydration
• Repetitive hospital admissions for the same condition
• Frequent injuries (especially if inconsistent with the story given)
• Refusal to undergo a physical exam, and/or doctor or hospital switching after injuries are sustained

Also, a family history of abuse, stress, or drug or alcohol abuse increases the likelihood that mistreatment will occur. Supporting caregivers, referring them to counseling, or supplementing care with professional services help prevent abuse.

If a staff member or volunteer suspects the abuse or neglect of a patient, he/she should report it immediately to the agency administrator or Volunteer Coordinator. PruittHealth Hospice adheres to all relevant state and federal laws concerning the reporting of suspected or actual resident/patient abuse, neglect or exploitation.

Please review the policy on abuse and neglect.

Universal Precautions and Infection Control

Universal precautions are standards of the condensed safety practices of OSHA (Occupational, Safety and Health Administration) along with the CDC (Center for Disease Control) that guides good healthcare practices.

These guidelines should be followed when visiting patients:
• Wash hands with warm water and an antibacterial soap before and after any contact with the patient. Hand washing is one of the most important and easiest practices used to prevent transmission of blood-borne pathogens
• Use disposable gloves any time you come into contact with blood or body fluids, or linens that may be soiled.
• Wear mask and eye protection or a face shield to protect mucous membranes of the eyes, nose, and mouth during patient activities that are likely to generate splashes or sprays of blood, body fluids, secretions, and excretions
• Dispose of gloves and disposable pads and dressings in a plastic bag
• Use disposable supplies whenever possible
• Clean any spills of body fluids with a freshly prepared solution of 1 part household bleach to 10 parts water. Surfaces in the home may be disinfected with this solution for cleaning purposes
• Use a barrier, such as a piece of paper between your personal items and any surface in the home. Throw away the barrier when you leave the home
• Wash hands and other skin immediately and thoroughly if contaminated with blood or other body fluids.

Please review the policy on Universal Precautions and Infection Control.

Emergency Preparedness and Safety

Safety education and review of the evacuation home plan are important areas to assess. Each admission to our services should contain the home safety guidelines and education provided for safety. As a volunteer if you are in a home or healthcare center, be prepared for any emergency experience.

Even though you are exposed to many hazards every day, you can handle and avoid these risks by being aware of your situation, following basic safety rules and using common sense.

Disasters

Emergencies or disasters can occur at any time and without warning. Healthcare workers need to be prepared for any disaster, like fire, tornado, hurricane or a bomb threat.
An important part of keeping patients, caregivers, families, and staff safe is to ensure that everyone:

- Knows safety and fire procedures
- Recognizes fire hazards
- Knows locations of fire extinguishers and fire alarms (home and facility)
- Has a planned emergency exit route for each home.
- Keeps personal vehicle well maintained
- Knows how to respond to threats of violence or aggression from patients, family members, or household pets

**Disaster Supply Kit**

The Center for Disease Control recommends that everyone has an emergency plan and a disaster supply kit with supplies for at least three days.

This kit should include at a minimum:

- Water
- Dried or canned food
- Flashlight and batteries
- Fire supplies; matches in water proof bag
- Prescription medications
- Digital thermometer
- Personal identification
- Clothing, blankets
- List of important phone numbers
- First Aid Kit

**Job-Related Hazards**

Healthcare workers are faced with different types of hazards and should know how to avoid them and how to handle them if necessary.

**Electrical safety:**

- Keep cords away from heat and water
- Use appropriate grounded, three-hole electrical outlets
- Never break or bend the third prong on a grounded plug

**Fire safety**

- Know where all the exits are located
- Plan emergency routes for quick exit
- Identify locations of smoke detectors and telephones
- Know how to use a fire extinguisher

**Oxygen Use**

- Keep oxygen away from direct heat, open flames, or flammable materials
- Avoid using aerosols around the oxygen to prevent fire
- Prevent smoking within 10 feet of oxygen equipment
- Avoid using electrical appliances (razors and hair dryers) while using oxygen

**Personal protective equipment**

Follow PruittHealth Hospice’s policy on the appropriate PPE (personal protective equipment) which provides a barrier between your body and dangerous hazards.

**Glove removal and hand washing**

Correct use of gloves and proper hand-washing procedures are vital for your safety. Hand-washing keeps from transferring contamination to other areas of your body, to other patients, or to your personal environment.

**Fire Safety Procedures: RACE**

When fire occurs, the first 3-5 minutes are the most critical for safety. One of the best safety practices is to know what to do in a fire emergency and to practice in advance how to carry out those instructions. Theory is great, but there is no substitute for hands-on experience. Practice using a fire extinguisher.

R Remove all patients and others from the immediate vicinity of the fire

Plan and practice what to do before the emergency happens. During an emergency is not
the time to ask questions or refer to an emergency plan.

Identify your patients and their capabilities or limitations.

Be familiar with techniques to transfer non-ambulatory patients. Ambulatory patients need blankets to wrap around them. Patients that require a wheelchair will need your immediate assistance; cover them with a blanket and remove them from the area.

Activate the alarm and notify staff that a fire exists

- Know where the fire alarms are located
- Be prepared to activate the alarm
- Follow the directions of the person in charge

Contain the fire

- Contain the fire and smoke by closing doors and windows
- Turn off oxygen or electrical equipment being used in the general area of the fire
- Clear any equipment from corridors and all exits

Remember; do not use elevators if there is a fire

Extinguish the fire

Extinguish the fire with a fire extinguisher on a small fire that has not spread to a larger area. Use the type of extinguisher according to the type of fire.

- Type A extinguishers are filled with water and are used to put out paper and wood fires
- Type B extinguishers are used for grease and oil fires
- Type C extinguishers are used for electrical fires

Extinguishers marked ABC may be used on all three types of fires.

When the fire alarm is activated, remove the nearest fire extinguisher from the wall and carry the extinguisher upright to the fire.

Use the four RACE steps to extinguish the fire.

Personal Safety

Practice personal safety by using strategies to minimize risks to your personal safety when making visits to a patient’s home or healthcare facility patients.

- Know the area that you are visiting; you may need to make a trial run before the first official visit.
- Plan the safest route to and from the patient’s home by making a note of the locations of nearby police stations, hospitals, and restaurants.
- Schedule and set up visits based on the knowledge of the area and the patient. Make sure your supervisor is aware of the location of the visit, estimated arrival time and duration of the visit the first time you go or every time if the area or patient is one of concern.
- Dress conservatively. Clothing should not restrict your movements. Wear comfortable shoes with nonskid soles that allow you to move quickly and safely.
- Wear light-colored clothing during the evening visits to ensure visibility.
- Avoid parking in underground parking lots and parking far away in isolated areas.
- Roll windows up and lock doors.
- Don’t leave personal items visible in the car.
- Stay alert and mindful of your surroundings.
Patient’s Visit

- Do not give your personal phone number to patients. When placing a call to a patient’s home, be aware of the potential “call display” feature. To block the call display, press “*67” before making the call.
- Never enter a home unless you have previously scheduled a visit.
- Exercise care in hallways, elevators and stairwells.
- Do not enter the home where there are visible signs that could be a threat to your safety (drugs, alcohol, and weapons) or where your instinct tells you not to.
- Pause for a few seconds when entering someone’s home to assess the situation and plan a response.
- Do not remain at a visit if a patient, a visitor or family member are intoxicated, abusive, inappropriately dressed or when sexual comments and innuendoes are made.
- Leave when you are told to leave.
- Sit with a good view of the bedrooms or the hall to the bedrooms.
- Always know an exit route, do not let yourself get cornered.
- Listen to your instincts.
- If someone makes you uncomfortable or your intuition says something is not right. REMOVE yourself immediately and report your what you were feeling to your Volunteer Coordinator.

When leaving a patient’s home, healthcare center or the inpatient unit:

- Have car keys in hand before leaving to avoid delays in entering the car.
- Keep your car keys on you at all times.
- If the neighborhood appears dangerous, ask one of the patient’s family members to escort you to the car.
- Check the outside of your car, the front and back seats before getting in.

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Story Remembered

The Atlanta PruittHealth Hospice office had a Japanese volunteer serve at Lilburn Health and Rehab Center where all of our hospice patients at that time were bedridden. One of her many talents was origami, the Japanese art of paper folding and sculpture. Realizing that our patients spent 16 to 18 hours every day facing the ceiling, she created a mobile to hang above each patient’s bed.

Every other Saturday, lifeless colored paper emerged into a unique animal. Each animal became part of a menagerie of animals that was a mobile floating through the air, a moving art creation that developed each time she came to volunteer.

Patients and staff were entertained by her delicate creations, and they anticipated and watched as each mobile took on new depth, color and style. Every new animal changed the complexity of the mobile and gave new meaning to the concept of environmental stimulus.

Scattered throughout the building, there were origami mobiles for the enjoyment of everyone.

Until she moved away, this volunteer enriched all our hospice patients, visitors and staff’s lives with her presence. When she was in the building, she was creating, when she wasn’t there, her gifted creations were reminders of her creative gifts.

Nancy Jacob
Social Worker
PruittHealth Hospice
Other Ways that Volunteers Serve Hospice Patients

Some volunteers with great patience and talent quilt, crochet and knit wonderful gifts of hats, afghans, shawls, and bibs. These volunteers never physically meet the patient or family, yet each one touches the patient with the hours of time woven into a tangible gift that endures beyond that patient’s life.

In the spring, Linda Scott at Peachtree Christian Hospice (our inpatient facility) called to say that a lady had dropped off a bag of handmade lap quilts and afghans.

I called Frances to thank her. No answer, no voice mail. I sent a thank-you note in the mail offering to take her to lunch. I tried several times before I actually left a message asking how long it took to create these beautiful gifts.

Frances called back and left a voice mail:

60 hours for each lap quilt, 10 in the bag (600 hours)  
40 hours for the afghans, 4 in that bag (160 hours)

Some weeks later, I was watching a volunteer select quilts and afghans for her patients; as she opened each quilt, she said, “this one looks like Mrs. G…and this one definitely fits Mr. M.”

Her joy was in handling each one, absorbing the bright colors: one had a fall look, oranges and yellows and browns; one was red and white and black (GA colors, she commented); one was the small patch look that reminded her of her grandmother’s work; a variety of designs…large blocks…small pieces with different shapes…some blue, some pink…all a kaleidoscope of color.

Each quilt shouted love and magnificent handiwork.

I sent Frances another note and again offered lunch. She called in a few days, left me a voicemail saying that she was busy, appreciated the lunch offer, but I didn’t need to do that. Also, she said, “I’ll have more quilts for you soon.”

I called and offered to pick them up and take her to lunch. Linda called in a few weeks to say another batch had arrived.

I picked up two bags this time: 10 quilts (600 hours) and 5 Afghans (200 hours). Frances made the quilts, and Blanche (her neighbor) made the afghans. I sent both of them thank you notes.
The next week, I called Frances. She thanked me for calling and offering lunch, and said, “I don’t eat much ... and I’m going out of town on another mission trip with my church... Thanks for all the calls.”

During the holidays, we had a staff and volunteer luncheon. Volunteers who couldn’t attend the luncheon were mailed a note and gift. I wrote a separate note to Frances trying to explain that her gifts not only touched patients and family members, but gave special pleasure to the volunteers who delivered these glorious gifts. She would be receiving notes from the volunteers who delivered her quilts.

Within a couple of days... I received a hand-written note from her:

Dear Doris,

Thank you so much for the gifts. You are very kind to give them to me. I really don’t deserve thanks for the quilts. I get pleasure making them. I am 88 years old and thank God that I am able to do something worthwhile. I also make crochet/knit hats for whoever needs them. I hope to have some quilts for you in the next few weeks. Thanks again and may God bless you.

Frances F
Hospice/Bereavement Ministry

My mother died of cancer in July 1991. She was a retired nurse and a hospice volunteer. Being with her when she died changed my feelings about the needs of a dying person.

I was ordained as a deacon at Smoke Rise Baptist Church in January 1992, and two of my deacon families were cancer patients. Through my visits with them and my experience with my mother, I realized this was an area in which I wanted to serve.

In August of 1993, I took hospice training with Peachtree Hospice; our minister, Dr. Truett Gannon, was interested in starting a Hospice Ministry at Smoke Rise. Rosemary Queen, Peachtree’s Volunteer Coordinator was willing to offer a volunteer training at our church with a minimum of 6 participants.

In November of that year, we trained 10 Smoke Rise members, and we found that most were interested in the Grief and Bereavement part of this program as well. So our ministry team began with hospice training which lead to the formation of a Bereavement Ministry as well.

We purchased copies of Good Grief by Granger Westburg and gave it to all members with losses in their immediate family. Soon, we turned to the Sunday school teachers and Deacons to help with this ministry. Dr. Norma Green volunteered to facilitate a grief support group, and we opened this up to the community, making this ministry an in-reach and outreach one for our church.

In 2000, Julie Cannon started facilitating these groups, and Julie and I put together “Dealing with Grief During the Holidays” workshop, which is offered every year.

Elizabeth Byars
Home Hospice Volunteer
Peachtree Christian Hospice

Elizabeth Byars is a wonderful example of how one person can touch and positively affect so many other lives. She understood and valued hospice work, long before many others of her time. Her passion and voice for the need for trained volunteers lead to the creation of a trained hospice team and a bereavement program in her church that began in 1993 and is still active today. Her story is one that could be modeled in any church:

• A church that has trained hospice volunteers available to family members when needed
• A church that has an on-going grief and bereavement program for those members who have survived the loss and death of a loved one
• A church that opens these ministries to neighbors and community
Endnotes:


3 Biewen, “The Hospice Experiment-Florence Wald.”

4 Biewen, “The Hospice Experiment-Dehumanized Dying.”


7 Ibid.

8 Madison-Deane Initiative, Pioneers of Hospice video.


10 Biewen, “The Hospice Experiment-Florence Wald.”

11 Mattson, “She saw Hope in Hospice.”

12 Biewen, “The Hospice Experiment-Florence Wald.”

13 Mattson, “She saw Hope in Hospice.”

14 Ibid.


17 Biewen, “The Hospice Experiment-St. Christopher’s.”


24 Mattson, “She saw Hope in Hospice.”


32 Ibid., p. 42.

33 Ibid., p. 49.

34 Ibid., p. 50.


36 Ibid.


42 Poem written by Dr. Ralph Roughton, M.D., Atlanta, Georgia. Permission granted verbally. May 2007.
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Glossary of Terms:

**Advance Directives**

Advance Directives are written instructions about future medical care, in the event that one becomes unable to communicate these instructions.

**Anticipatory Grief**

Anticipatory Grief is an experience of grief that occurs prior to the death of a loved one and involves the expectation of emotional pain and life changes the loss will bring. Although anticipatory grief does not completely prepare one for the emotional experience of the actual loss, this process may allow time for resolving unfinished business.

**Bereavement**

Bereavement is the general state of being that results from having experienced a significant loss. The components of bereavement encompass a wide range of reactions - emotional, cognitive, spiritual, behavioral, and physical.

**Capacity**

Capacity refers to the ability of an individual to understand the information he or she is being asked to act upon in order to give informed consent. Capacity is not a legal term.

**Competent vs. Incompetent**

Adults are considered to be legally competent to give informed consent unless the courts have determined otherwise.

Incompetence is a legal term meaning that an individual has been adjudicated as not mentally competent to make decisions in his or her own behalf. A guardian is then appointed who will act on the individual's behalf.

**Complicated grief**

Complicated grief is identified by the extended length of time of the symptoms, the interference in normal function caused by the symptoms, or by the intensity of the symptoms (for example, intense suicidal thoughts or acts). Complicated grief may appear as a complete absence of grief and mourning, an ongoing inability to experience normal grief reactions, delayed grief, conflicted grief, or chronic grief. Factors that contribute to complicated grief include an unexpected death, the gender of the person in mourning, and the relationship to the deceased (for example, an intense, extremely close, or very contradictory relationship).

**Curative care**

Treatments or procedures that attempt to cure the disease or medical problem.

**Grief**

Grief refers to the psychological process of regaining equilibrium. Grief feelings may include intense emotional pain, suffering, or sorrow. The grieving process requires reorganization on both emotional and cognitive levels.

**Guardian**

A person who has been legally appointed to make decisions on behalf of an individual who has been adjudicated as not mentally competent to make his or her own decisions.

**Informed Consent**

This is a legal term referring to the right to make medical treatment decisions. Under state law, it typically includes the right to be informed of one's medical condition and prognosis, the risks and benefits associated with a recommended procedure or course of treatment, and what alternatives exist.

In the case of mental incapacity, an individual's right to give or withhold informed consent usually passes to the person's legal representative.

**Interdisciplinary team approach**

Hospice work incorporates the expertise of all disciplines which includes the hospice team as well as the patient's attending physician.
**Medicare payment**
A federal insurance benefit available for U.S. citizens over the age of 65 who have worked 40 quarters (10 years) before their 65th birthday. Physically or mentally disabled adults under 65 years of age who have been disabled for 2 years qualify for Medicare options, also.

**Medicaid**
Available only for a United States citizen or permanent resident who is low income, aged, blind, or disabled.

**Mourning**
Mourning is the public expression or sharing of the feelings of grief. This usually takes the form of rituals such as a funeral service or wearing black. The period of mourning can vary by culture, and variation is often displayed by individuals and families within the same culture.

**No-pay**
An indigent patient who has no insurance, and does not qualify for Medicaid benefits.

**Palliative care**
Comfort care measures that provide relief of symptoms and pain control.

**Psychosocial**
Psychosocial is a term encompassing the psychological, behavioral, social, and environmental aspects of an individual.

**Private Pay**
An individual who doesn’t need or carry insurance; this person pays for all medical needs out of their pocket.

**Private Insurance**
Insurance offered by an employer as a paid employee benefit. If the person is self-employed, the individual takes out an insurance policy for medical coverage. This insurance may also be a supplemental policy that the individual has paid for separately.

**Self-Determination**
Self-determination is the right of competent adults to make their own medical treatment decisions, including completing advance directives.
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Sometimes, Linda Scott and I taught volunteer classes together, so we could share information about inpatient, home and healthcare center patients and because it’s more fun for us to do it together. One Friday night, we were finishing a training class, when an ambulance arrived with a patient.

Linda assisted the EMT’s in getting the patient to the right room on the designated hall. I was cleaning up the training room and visiting with the some of the volunteers when someone began banging on the front door. I went immediately to try and open the door, but it was coded...locked. He was banging and punching on the key pad at the same time. He yelled to me, “what’s the code?”, and my response of “I don’t know” infuriated him.

“What do you mean you don’t know...how can you not know?”

I was explaining that I didn’t work there, but he wasn’t listening to me. I had sent someone to get Linda, and I was explaining that to him. Before she could get to us, he punched in the right combination. The door unlocked, and he stormed past us without a word; his silence and anger more daunting than his yelling.

The volunteers exited out those same doors, and I went to tell Linda what happened.

The next morning I was at PCH early to set up for our class. A man was standing in the hallway outside the training room crying. I went to him and asked if I could help. He turned around, laid his head on my shoulder and sobbed, saying, that his wife was dying; he had brought his children to see her this morning. Eventually, he pulled away, embarrassed, apologized for crying all over me and went down the hallway to her room.

I told this story during class that day.

The angry man from the night before who yelled at me was the same one crying on my shoulder that morning. He didn’t remember me from the night before.

These types of stories are every day...ten times a day episodes of inpatient experiences. Hospice family members, caregivers and patients give you an opportunity to reach beyond yourself to be to be present with suffering and grief in a way unlike any other experience.

Your name or your face may never be remembered or known, but your presence will have made a life-time of difference.

Doris Nelms
Volunteer Coordinator
PruittHealth Hospice of Atlanta