“A journey of a thousand miles begins with a single step.”

—Lao Tzu
Thank You for allowing Cornerstone Hospice & Palliative Care to assist you and your family during this difficult time in your lives. Cornerstone Hospice care is devoted to easing the physical pain and emotional upset caused by life-limiting illness while assisting you and your loved ones to live life to its fullest. This booklet will acquaint you with our services and provide information about pain and symptom management, nutrition, and other measures you can take to maintain comfort. Please read it as you are able. If you have questions, please ask any of your Cornerstone team members during their visits, or call Cornerstone Hospice any time, day or night, seven days a week. We are always here for you.

Chuck Lee, President & CEO
Cornerstone Hospice & Palliative Care, Inc.
Our Mission

The mission of Cornerstone Hospice is to make quality Hospice care available to all persons, their families, and those affected by death and dying in our community; to advocate effectively for patients’ comfort, dignity and choice; and to be recognized as the leading resource in clinical, ethical and spiritual issues of dying and grief.
## Contents

### SECTION I — INTRODUCTION TO HOSPICE CARE
- The Cornerstone Interdisciplinary Team ........................................... 1
- Call Cornerstone Hospice First ......................................................... 3
- Your Handbook ................................................................................. 4
- A History of Hospice ........................................................................ 5
- Cornerstone Hospice Services ......................................................... 5
- Hospice Levels of Care ..................................................................... 5
- Additional Patient and Family Services ........................................... 6

### SECTION II — PATIENT-CENTERED CARE
- The Family: Being a Caregiver .......................................................... 19
- Interdisciplinary Team ....................................................................... 20
- Communication with the Team .......................................................... 21
- Communication between Patient and Family ..................................... 21
- What Needs to be Said ....................................................................... 21
- Communication with Friends and Visitors ......................................... 22

### SECTION III — THE PATIENT
- Unknown Territory ............................................................................ 23
- Fear of the Unknown for the Family .................................................. 23
- Fear of the Unknown for the Patient .................................................. 23
- Fear of Suffering ............................................................................... 23
- Spiritual Support ............................................................................... 24
- Loss of Independence ........................................................................ 24
- Time and Space Perception ............................................................... 24
- Sacred Spaces .................................................................................. 25
- Leaving a Legacy .............................................................................. 28

### SECTION IV — SYMPTOMS AND TREATMENTS
- Abdominal Swelling ........................................................................ 29
- Ambulating and Transferring ............................................................. 29
- Anxiety and Restlessness ................................................................. 29
- Bathing ............................................................................................. 30
- Bed Sores or Pressure Ulcers ............................................................. 30
- Blood in Urine .................................................................................. 30
- Confusion ........................................................................................ 31
- Constipation ..................................................................................... 31
- Cough ............................................................................................... 32
- Dehydration ...................................................................................... 32
- Depression ....................................................................................... 32
- Diarrhea .......................................................................................... 32
- Difficulty Breathing or Shortness of Breath ....................................... 32
- Difficulty Swallowing ....................................................................... 33
- Dizziness ......................................................................................... 33
- Dry Mouth ........................................................................................ 33
- Fever and Body Temperature Changes ............................................. 33
- Hemoptysis (Blood in Sputum) ......................................................... 34
- Hiccups ......................................................................................... 34
- Indigestion ....................................................................................... 34
- Insomnia ........................................................................................ 34
- Itching .............................................................................................. 34
- Jaundice .......................................................................................... 34
- Medicines ....................................................................................... 35
- Comfort Kit ..................................................................................... 35
- Muscle Spasms ............................................................................... 35
- Nausea and Vomiting ....................................................................... 35
- Pain ................................................................................................. 36
- Poor Nutrition or Loss of Appetite .................................................... 37
- Sore Mouth ..................................................................................... 37
- Seizures .......................................................................................... 37
- Swelling or Edema ......................................................................... 37
- Unconsciousness ............................................................................. 38
- Urinary Incontinence ....................................................................... 38

### SECTION V — CHALLENGES
- Infection Prevention ........................................................................ 39
- Medication Use and Safety ............................................................... 39
- Oxygen Safety ................................................................................ 40
- Safety in the Home .......................................................................... 40
- Disaster Planning ............................................................................ 41

### SECTION VI — WHEN THE TIME COMES
- Introduction ..................................................................................... 43
- What the Journey Can Look Like ..................................................... 43
- The Final Moments ......................................................................... 44
- Passing ............................................................................................ 45
- Confirmation of Death ..................................................................... 45
- Disposal of Medications .................................................................. 45
- Equipment Pickup ........................................................................... 45
- Funeral Planning ............................................................................. 46

### SECTION VII — GRIEF AND BEREAVEMENT
- Anticipatory Grief ........................................................................... 47
- Bereavement .................................................................................... 48

### SECTION VIII — ADDENDA ................................................. 49
The Cornerstone Interdisciplinary Team
Cornerstone Hospice provides care and support to the patient and family at the end of life through a team of skilled professionals known as the interdisciplinary team.

Team Name

Phone Number

Hospice Physician
Visits patients and coordinates care, working closely with the team to provide care and symptom management.

My Hospice Physician

Patient and Family
You and your family/caregiver are the heart of the team and are encouraged to participate in all decisions involving your care

Team Assistant
The team assistant fields phone calls, coordinates messages and will be your liaison between you and the team. Anytime you have a need or you want to speak with a member of the interdisciplinary team, the TA will assist you.

My Team Assistant

RN Case Manager (Hospice Nurse)
Your Hospice nurse provides the professional guidance needed to care for you at home. He/she will visit you and set up a schedule of visits to help meet your needs for comfort, perform procedures ordered by the doctor, assist with medicines and discuss any other concerns you may have. Since not all concerns occur during the daytime, there is a Cornerstone nurse available to you for emergencies 24 hours per day.

My RN Case Manager (Hospice Nurse)

Social Worker
Your Hospice social worker can help you and your family with emotional problems that come with critical illness. He/she can also assist with problem-solving in a crisis, reviewing alternative living arrangement, exploring financial needs and utilizing other community resources.

My Social Worker

RN Team Manager
Each team is managed by a regional team supervisor. When calling the office, you will usually speak to the supervisor who will either assist you personally or send someone to help you.

My RN Team Manager
Hospice Aide
Hospice aides provide personal care such as bathing, hair and mouth care. The length and frequency of their visits are determined by patient needs and plan of care.

Chaplain
Hospice chaplains are non-denominational clergy who provide spiritual support appropriate to your wishes, or will contact the spiritual support person of your choice if requested. They assist with final arrangements as requested.

Bereavement Counselors
Bereavement counseling or support, an important part of Hospice care, is provided for the patient and loved ones. Bereavement support is offered to the families for at least one year. Bereavement can begin during the time care is being provided to the patient and continues after the patient has passed. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, individual counseling, and support groups.

Hospice Volunteer
Hospice trained volunteers are an integral part of the Hospice team and essential to the Hospice organization. They play vital roles in supporting patients and families and provide many special comfort and support services that distinguish the Hospice program.

Community Physician
Your physician may continue to serve as your doctor and work with members of the Cornerstone team including our physician to manage your care.

“Unity is strength. When there is teamwork and collaboration, wonderful things can be achieved.”
—Mattie J. T. Stepanek

My Hospice Aide
My Chaplain
My Bereavement Counselor
My Community Physician
Call Cornerstone Hospice First

In the event of a crisis, there is always a Cornerstone Hospice team member available to you 24 hours a day, 7 days a week.

When calling Hospice, please state the following:

“I would like to speak to my Hospice nurse/RN Case Manager about (patient’s name). The patient is on the (identify team) Team. Please have the nurse call (your name) at (your phone number).”

To contact your Hospice team member, call

TEAM

PHONE

IN THE EVENT YOU ARE UNABLE TO REACH A CORNERSTONE HOSPICE TEAM MEMBER, CALL

888.728.6234

24 HOURS A DAY // 7 DAYS A WEEK

Please call for the following reasons:

• For any emergency
• For any symptom management or uncontrolled pain
• For any significant change in patient’s condition
• For questions regarding medication management
• For any immediate concern regarding the patient
• When your physician orders or changes medication
• When your physician orders testing or treatment; such as, chemotherapy or radiation therapy, surgery, transfusion, laboratory test, or X-rays
• If you will be traveling outside of your county
• If you will be seeing a physician, receiving testing or going to a hospital
As you begin your journey with Cornerstone Hospice care, we hope that this handbook will offer you guidance in the physical care of the terminally ill, teach you what is happening to the body, and help you understand the symptoms you can expect. We have also included suggestions for you and your family to help maximize the living moments while on your end-of-life journey. We are honored that you have asked us to accompany you on that journey, and we will be by your side every step of the way.
History of Hospice Care

The word “hospice” comes from medieval times when “hospitality” shelters provided rest for sick or weary travelers on long journeys. Modern day Hospices focus on care rather than cure. Hospice care concentrates on physical, social, emotional, and spiritual needs. Satisfying these needs helps people achieve comfort so they can focus on living each day as fully as possible. Comfort to most people is being free of pain and remaining in their own environment surrounded by family and friends. Family members, with the help and guidance of the Hospice team, share in the care of their loved ones. Both the family and the patient find this a fulfilling alternative to institutional health care for the dying.

The first Hospice was established in England in 1967 to provide special care for persons making their journey through a terminal illness. The first hospice in the United States was established in 1974. Cornerstone Hospice was founded in 1984 as a 501(c) 3, not-for-profit healthcare agency to serve patients and families seeking quality and dignity in their lives while coping with a terminal illness. We are licensed by the State of Florida and certified by Medicare and Medicaid. Hospice is respected as the organization that provides quality professional care to people with any serious, complex illness while also assisting their families.

Cornerstone Hospice Services

Each Cornerstone Hospice patient/family has special needs and requirements, making each care program unique. Individual services may include:

- Nursing visits
- Visits by Cornerstone Hospice Physician and/or ARNP
- Visits by our interdisciplinary team members as needed
- On call 24 hours per day, 7 days per week
- Coordination with patient’s physician
- Family/caregiver training for patient care
- Education concerning illness, what to expect as disease progresses and how to cope with limitations
- Hospice Aide/Personal Care services
- Social services
- Spiritual counseling and support
- Professionally trained volunteers
- Medications, medical equipment and supplies related to the terminal disease process/prognosis
- Family respite care, as needed
- Supportive Care, as determined by Hospice staff guided by federal regulations, provided in the patient’s place of residence, nursing homes, and assisted living facilities
- Inpatient care, as determined by the Hospice staff, in hospitals and Hospice units
- Therapy services as ordered by physician
- Bereavement support including grief counseling and support groups

Long-Term Care Services

Those who reside in an assisted living facility or nursing home are entitled to Hospice care in the same manner as those who live in their own homes. The purpose is to provide the same special care that a Hospice patient receives in other settings. In an assisted living facility setting, this may enable the patient to remain in that facility when the level of care increases beyond what is permitted without Hospice involvement. In both an assisted living facility and a nursing home, the addition of Hospice care is not designed to replace the care given by the facility, but to enhance the level of care needed to provide the greatest comfort and dignity.

The Cornerstone staff works with the facility and patient to design a plan of care that addresses issues such as dementia management, pain control, weight loss or any problem related to condition changes. In addition, Hospice staff helps to provide increased communication and problem solving between patient and facility, thus enhancing the patient’s quality of life. Hospice also provides support, communication, education and assistance to the facility staff, who are the designated caregivers 24 hours a day, 7 days a week. Hospice staff members are invited guests into a facility and honor all of its policies and procedures. All facility issues should be directed to the appropriate unit manager, director of nursing or administrator of the facility.

Hospice Levels of Care

1. ROUTINE CARE is provided wherever a patient lives; i.e., in the Home, Nursing Home, Assisted Living Facility, hospital, or Hospice house or unit. The patient is visited by team members, including the Hospice physician. The services of special providers such as a dietitian, physical, occupational or speech therapists with a physician’s order are available as each patient’s condition requires.
2. **RESPITE** is provided at a contracted, skilled nursing home for short periods to allow the family to rest or be away for a period of time up to five days, as needed.

3. **INPATIENT CARE** is also included in the Medicare, Medicaid, TriCare, and the benefits of many private insurance plans. It provides for the patient to be hospitalized in local contracted hospitals, Hospice houses, inpatient units, or beds in a local contracted nursing home to receive acute symptom management which cannot be conducted in the home. Treatment is limited to management of symptoms related to the Hospice diagnosis.

4. **SUPPORTIVE CARE** is a higher level of care provided when the hospice patient demonstrates a need for skilled intervention for symptom management. Supportive Care is for a limited time only and must meet certain criterion set by Medicare.

**Additional Cornerstone Hospice Patient/Family Services**

Some patients and families need or require additional services. Perhaps a primary caregiver is not available as needed or is too frail to provide adequate care. Cornerstone Hospice offers resources to help meet these and other special needs.

**CORNERSTONE SALUTES!** Cornerstone Hospice & Palliative Care has enhanced care and services for American veterans experiencing life limiting illnesses. Cornerstone SALUTES! is a comprehensive Veteran’s Hospice program that respectfully celebrates veterans who served our country, at home and abroad. Many factors can influence a veteran’s end-of-life experience. Among them are age, branch of service, enlisted vs. drafted, rank, combat or POW experience. Some combat veterans who have faced death in wartime are able to integrate their experiences into their lives and then become better equipped emotionally to cope with their own deaths. Many other veterans who had their lives traumatically changed suffer from social isolation, substance abuse and anxieties. Yet for some veterans, the effects of combat may not surface until they are very sick and facing end of life. Several decades after participation in hostile engagements, some veterans may experience anxiety, agitation and vivid memories connected to war experiences. Veteran patients have very specialized, individual needs that are not solely based on medical, emotional, physical, social and spiritual issues. Their specialized care plan identifies and treats any differences that veteran patients experience at the end of life.

To honor veteran patients and their families by meeting their unique needs, Cornerstone SALUTES! offers a team of professionals and volunteers, specially trained in a program designed by national VA expert Deborah Grassman and patterned under VA guidelines. Cornerstone SALUTES! services include:

- Specially trained staff to meet the unique needs of our veterans by a national VA expert.
- A tailor-made Pinning Ceremony for the veteran patient and family by a veteran member of our staff or a veteran volunteer. A special pin and a Certificate of Appreciation are presented to the patient.
- Annual Journey of Remembrance offered exclusively for veterans’ families to pin them, thank and honor them for their part in helping to keep America free. “A soldier does not fight alone... it is a family effort.”
- Networking with other veteran services helps us to work together and to join in the fabric of veteran support in all of our communities.
PET PEACE OF MIND program offered through the Cornerstone Hospice Foundation is designed to assist Cornerstone Hospice patients and their families who have pets. The program allows a patient to keep his/her pets for as long as possible and assists with placing them when and if it becomes necessary.

Cornerstone Hospice staff addresses the physical, emotional, psychosocial and spiritual needs of individuals with life-limiting illnesses while offering guidance and support to those who share their lives… including the family pet. Family pets are included in the patients’ care planning so patients have an opportunity to consider making proper arrangements for pets when they go into the hospital or a Hospice house.

Pet Peace of Mind allows patients to complete their life’s journey without worrying about their pet’s current or future needs. The initiative provides volunteer pet care services for patients who are unable to care for their pets while on Hospice.

Through pet-loving volunteers and donations by the community, Pet Peace of Mind offers basic in-home care, dog walking, pet waste clean-up, bathing and grooming, pet sitting and boarding, pet food and cat litter, flea and tick treatment, and/or routine vaccinations and medications, as well as transportation for veterinary visits or grooming.

Houses & Inpatient Care

At Cornerstone Hospice and Palliative Care, we recognize some patients may not be able to remain in their homes. They may need inpatient care for pain and symptom management or supervised, around-the-clock assistance. Cornerstone’s Hospice Houses offer care in a home-like setting where patients can be surrounded by friends and family, at any time of day. They are staffed by compassionate and skilled Hospice nurses and nursing assistants. Our Hospice Houses are places where loving words, respectful listening, shared remembrances, a touch or embrace, can bring peace and closeness during the precious time that remains for those nearing the end of life. Here, patients find acceptance, hope, empathy, and encouraging self-help.

In the areas that we don’t have a free-standing hospice house there are other options for the General Inpatient level of care. This level of care can be provided in a contracted hospital or Skilled Nursing Facility that meets the staffing requirements of General Inpatient Care.

Cornerstone operates six hospice houses and inpatient units in Lake, Sumter, and Orange counties. Each facility offers:

- Private and semi-private comfortable inpatient rooms with room for visiting friends and family.
- Common family areas include refreshment area, quiet rooms and access to mobile Internet devices
- Wi-Fi and iPads available in all rooms
- Visitation at any hour
- All services including nursing, social work, counseling, Hospice physician visits, personal care, medication and supplies provided just as they are in their own home.

Patients and/or their loved ones receive the same degree of quality and compassionate care that our in-home patients receive. Any Hospice patient from anywhere—even from outside our coverage area—may be accepted into one of these facilities.

Our Hospice team of Physicians, Nurses, CNAs, Social Workers, and Chaplains prepare a personalized care plan with each individual and his/her family or caregivers. The goal of the patient’s care plan may be to get symptoms under control or to see that person through his/her course of treatment.

To be eligible for inpatient care, a Hospice patient needs:

- Short-term acute pain or symptom management;
- Teaching following hospitalization; or
- Short-term emergent care
Frank and Helen DeScipio Hospice House  
2445 Lane Park Road, Tavares, FL 32778  
- Six Private Bedrooms  
- Opened in 1991  
- First free-standing Hospice house in Florida  
- Named for a founding Operations Board members  
- Serves patients and families in Lake County and the surrounding areas.

Lane Purcell Hospice House  
2294 CR 526E, Sumterville, FL 33585  
- Eight Private Bedrooms  
- Opened in 2009  
- Built on land donated by Glenn Wade, Dr. Lowell Clark, and John Manning  
- Serves patients and families in south Sumter County and the surrounding areas.

The Villages Hospice House  
601 Casa Bella, The Villages, FL 32162  
- Twelve Private Bedrooms  
- Opened in 2003  
- Golf cart accessible within The Villages  
- The Villages Serenity Center is a quiet retreat for meditation, prayer, and/or spiritual services. It provides a calm, peaceful setting for reflection and meditation.  
- Serves patients and families in south Sumter County and the surrounding areas.

Cornerstone Inpatient Suites at Winter Park Towers  
1111 South Lakemont Avenue, Winter Park, FL 32792  
Cornerstone Inpatient Suites is in a charming retirement community in the Orlando suburb of Winter Park. The facility is located in a private wing of Winter Park Towers with a separate entrance on the campus just for the suites.  
- Ten Private and semi-private Beds  
- Hospice wing opened in 2010  
- Serves patients in the greater Orlando area.
Mike Conley Hospice House
2100 Oakley Seaver Boulevard, Clermont, FL 34711
• Ten Private Bedrooms
• Opened October 2007
• State-of-the-art conveniences
• Constructed on land donated by South Lake Hospital
• Serves patients and families in south Lake County and the surrounding areas.

Cornerstone Hospice Care Center at Orlando Health
52 West Underwood Street, Orlando, FL 32806
Cornerstone Hospice joined ORMC at the downtown Orlando campus to open the only in-hospital hospice resource in the area with a dedicated, 24/7 hospice team. This additional attention ensures a smooth transition to another stage of care—home, long-term care or assisted living facility.
• Ability to care for high-acuity, hospice-appropriate patients
• State-of-the-art amenities in an intimate care environment
• 22-bed spacious suites that include a sleep sofa, sleep recliner and chairs in each room for comfort
• Feel more like quiet retreats than hospital rooms
• Reflection room with dim lighting and beautiful stained glass window is an intimate spot for quiet meditation or prayer.

COMMUNITY BEREAVEMENT—In addition to providing bereavement support to family members, friends, and patients of Cornerstone Hospice, we also provide bereavement support to anyone in the community who is struggling to cope with the loss of a loved one, be it a family member or a friend. This service is offered at our offices in Lake, Sumter, Orange, Osceola, Polk, Hardee and Highlands counties at no cost. Professional mental health counselors provide individual, one-on-one counseling as well as support group sessions, and work with both adults and children in the community what are grieving a loss in their lives. For those who cannot travel to our offices, we provide telephone sessions as well.

Cornerstone has assisted thousands of people in the often difficult journey through loss and change. No one needs to grieve alone. We can be contacted directly by those in need, or we accept referrals from law enforcement, the judiciary, schools and churches. Please do not hesitate to let us know if we may be of assistance to you or your loved ones. We are here to help.

Patient and Family Rights and Responsibilities
Cornerstone Hospice is dedicated to supporting you and your family, providing for your needs, answering your questions and enhancing your quality of life. To assure that your interests are protected, all Hospices comply with Florida law setting forth patient’s rights. These are your rights and the staff of Cornerstone Hospice wants you to have the information and support that you wish to have. Please feel free to ask questions.

Hospice recognizes that, in today’s world, “family” has become a somewhat flexible term. It may refer to all, or only some, of those traditionally thought of as family or it may refer to a “chosen” family, or a combination of both. Whomever you designate as your family is the family Hospice will honor.

Section 418.52(a)(1) of Patient’s Rights document states that a Hospice must provide the patient or representative with verbal and written notice of patient’s rights and responsibility. The notification must be presented in a manner and language consistent with the patient’s ability to comprehend the information.

(See Addendum A for full disclosure of Patients’ Rights and Privacy Statement.)
You and your family have the following rights:

- To be informed of your rights verbally and in writing in a manner understandable to the patient or representative.
- To be informed on the scope of services that Cornerstone Hospice will provide and specific limitations on those services.
- To receive information about the services covered under the Hospice Benefit provided by Medicare, Medicaid, Private Insurance and any other reimbursement source.
- To be informed of the cost of services that will be billed to the patient's insurance or to the patient.
- To be informed and to execute Advanced Directives as desired.
- To voice grievances regarding treatment or care that fails to be furnished.
- To the respect of the patient's property and person by anyone who is furnishing services on behalf of Cornerstone.
- To privacy, confidentiality, and security of health information; to have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with state laws and federal regulations.
- To exercise rights as a patient of Cornerstone and to be free from discrimination or reprisal for doing so.
- To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source and misappropriation of patient property.
- To receive effective pain management and symptom control from Cornerstone Hospice for conditions related to the life-limiting illness/Hospice diagnosis.
- To refuse all or part of care or treatment
- To choose your attending physician
- To be involved in developing your Hospice plan of care and to participate in all aspects of care and service.
- To receive care from a team of professionals who provide skilled, quality, comprehensive Hospice care as needed and appropriate, and to know who is providing services.
- To have access to Hospice care and services 24 hours a day, seven days a week.
- To receive care regardless of age, gender, national origin, sexual orientation, diagnosis, cost of therapy, source of payment, ability to pay, life circumstances at the patient's place of residence within the service area of Cornerstone.
- To receive information and answers to questions regarding the patient's health status, diagnosis, planned course of treatment, alternatives, risks, and prognosis so that the patient or representative can participate in the plan of care.

As a patient, you have the responsibility:

- To participate in developing the patient's plan of care and updating it as the patient's condition or needs change.
- To provide Cornerstone Hospice staff with accurate and complete health information.
- To remain under a physician's care while receiving Hospice services and to notify a Hospice staff member should the patient change his/her physician.
- To assist Cornerstone Hospice staff in developing and maintaining a safe environment in which the patient's care can be provided.
- To call Cornerstone Hospice prior to scheduling or having any tests or treatment or going to the hospital.
- To keep all medications, equipment, and supplies safe from harm or misuse.
- To inform your Hospice team if you have any problems, questions or complaints; or to contact the VP of Quality and Compliance and/or the VP of Patient/Family Services with any unresolved problems, questions or complaints.

(See the last page of Addendum B “The Privacy Statement” for additional contact information.)

Hospice Ethics Committee

Cornerstone recognizes that many complex issues may surround life-limiting illness for patients, families, caregivers and the community. Our Ethics Committee is available to assist you with ethical conflicts or difficult decisions that may arise during this time. For more information, or to request assistance from the Ethics Committee, please contact one of your Hospice team members.
Planning Ahead

Just as you make many practical plans ahead of time for any journey you take, planning ahead for your final journey can reduce fear and anxiety of the unknown, allow you to direct your care and affairs as you choose, bring loved ones closer by planning together, and ease the pain, adjustments and worries of those left behind.

These are important aspects of planning ahead that need to be discussed and organized. A Hospice staff member can assist you and your loved ones. Also see Personal Data sheet on page 17 of this booklet.

Wills

It is important to contact your lawyer to have an updated will drawn in this state to allow your wishes to be carried out.

Advance Directives

Hospice maintains a policy that strongly supports the right of an individual to make medical treatment decisions based on informed consent. Informed consent includes the right to be told of one’s medical condition, prognosis, treatments available, their benefits and risks, and the alternatives to treatment.

Hospice further recognizes the right of an individual to formulate advance directives if he or she chooses. If you have already executed any advance directives or if you do so in the future, please notify Hospice staff so that they may obtain a copy of the document for your medical record.

Participation in the Hospice program is in no way contingent upon whether one has or does not have advance directives. Hospice recognizes that this is an individual matter based upon personal choice.

WHAT ARE ADVANCE DIRECTIVES?

- A Living Will
- A Health Care Surrogate Designation
- A Durable Power of Attorney
- A Do Not Resuscitate Order

Preferably, these documents are written by you in advance of serious decline or injury.

WHAT IS A LIVING WILL? Written directions that explain your wishes if you become unable to make your own decisions. The living will takes effect when you are unable to make health care choices. In preparing a living will you should alert those closest to you and include the assistance of your doctor and/or attorney so that your wishes are clearly understood.

WHAT IS A HEALTH CARE SURROGATE? A written document in which you can name a family member, close friend or other person to make medical decisions for you if you become unable to do so.

WHAT IS A POWER OF ATTORNEY? A written document which specifies a family member, close friend, or other person to handle areas designated by the power of attorney. Generally, a power of attorney is only legal while the patient is alert and oriented, and could direct the designee to act on his/her behalf.

WHAT IS A DURABLE POWER OF ATTORNEY? A written document you can use to designate a family member, close friend or other person to handle medical/financial decisions and to handle financial obligations even if the patient is confused and not able to make decisions.

WHAT IS A DO NOT RESUSCITATE ORDER? Just as birth is a natural and expected process, so is death a natural physical process and life is expected to end. Allowing a natural death simply means not interfering with the natural dying process while providing care directed at keeping the patient as comfortable as possible. A Do Not Resuscitate Order (DNR) is a written document arranged between you and your doctor if cardiopulmonary resuscitation (CPR) is not desired when the heart and/or lungs stop functioning. The DNR is your written wish to allow the natural process to take place without the intervention of CPR. The DNR document must be easily visible in the home and on yellow paper. It is common practice to keep this form on the refrigerator.

(Please see Addendum D “Health Care Advance Directives...the patient’s right to decide” prepared by the Florida Agency for Health Care Administration. Also see forms for Health Care Surrogate/Proxy and Advance Directives.)
Financial Considerations

Our not-for-profit organization has helped thousands of patients and their families. Since 1984, Cornerstone Hospice and Palliative Care has made its services available to all terminally ill persons with life expectancy of 12 months or less and their families without regard to age, gender, national origin, sexual orientation, disability, diagnosis, cost of therapy, ability to pay, or life circumstances. We do not impose any value or belief system on our patients or their families and respect the values and belief systems of our patients and their families. Medicare, Medicaid and many other health insurance plans may cover all or part of the cost of Hospice services.

The Cornerstone Hospice staff will work with the patient, the family or loved ones, insurance providers and other resources, to assure that the patient receives all the benefits available.

Hospice Medicare

WHO IS ELIGIBLE FOR HOSPICE MEDICARE?
- Patients who are eligible for Medicare Part A.
- Patients whose Attending Physician and the Hospice Physician certify that the patient is terminally ill with a life expectancy of six months or less.
- Patients who choose to receive care from a Hospice program and who sign a Hospice Medicare Election Statement.
- Patients whose care is provided by a Hospice program certified by Medicare.
- Patients who are no longer seeking aggressive/curative care.

WHAT BENEFITS ARE COVERED UNDER HOSPICE MEDICARE? Hospice Medicare covers approved treatments and services related to the Hospice diagnosis. Community Attending Physicians continue to be paid through Medicare Part B. Treatments and services not related to the terminal diagnosis continue to be reimbursed by standard Medicare. If the treatment is not related to the terminal disease, the patient may be responsible for the Medicare deductible and coinsurance amounts. Hospice will be responsible for differentiating between related and unrelated services. Medicare will not pay for services that are related to the Hospice diagnosis and are determined by the Hospice to be aggressive or curative.

Patients who elect the Hospice Medicare benefit may be eligible to receive the following Hospice services under Medicare Part A:
- Visits from Hospice Team to Hospital, Nursing Home, Assisted Living Facility and Patient’s Home
- Coverage for both Homebound and Non-Homebound Patients
- Medical Supplies and Equipment that are related to the Hospice diagnosis
- Physical, Occupational, Speech and Dietary Consultants
- Related Outpatient Procedures and Lab Work
- From 8 to 24-hour shifts per day for Short-term Periods of Crisis
- Short-term General Inpatient Care in a contracted hospital or Hospice House as appropriate
- Five (5) days of Respite Care per billing cycle as appropriate
- Bereavement Services
- Social Services and Chaplaincy
- Related Pharmacy/Meds
- Hospice Physician/ARNP

HOME FACE-TO-FACE VISITS—Patients being re-admitted to Hospice services on or after the third Medicare Hospice benefit period are seen by the Hospice Physician or Advanced Registered Nurse Practitioner (ARNP) on or prior to readmission and/or Hospice benefit re-certification.

HOW LONG IS HOSPICE MEDICARE IN EFFECT? Special benefit periods apply to Hospice care. Hospice Medicare is provided and re-evaluated for two 90-day periods followed by indefinite 60-day periods when the patient is re-certified as having a limited life expectancy. The patient may stop Hospice care at any time and return to cure-oriented care. Should the disease stabilize, the patient’s physician may decide that the patient no longer meets the Hospice clinical guidelines. The patient would then be discharged from full Hospice care and returned to the traditional Medicare benefit. Hospice will assist with referrals to other community services, if needed. Full Hospice services will be available to the patient again if he/she meets the clinical guidelines at a later date. Medicare benefit will not expire as long as the patient remains clinically appropriate under the Medicare guidelines.
Hospice Medicaid

In the state of Florida, Hospice Medicaid is basically the same as Hospice Medicare. To become eligible, a patient must meet the financial criteria under the Department of Children and Families Services guidelines. The Hospice staff will assist you in completing these forms.

Medicaid eligible patients under the age of 21 can elect Hospice Medicaid while still receiving curative or aggressive treatment under the Concurrent Care for Children Program.

Champus/TriCare

Champus/TriCare military insurance benefits provide the same services under its Hospice benefit as Medicare and Medicaid.

Insurance Plans with a Hospice Benefit

A method of payment is coordinated between a patient’s insurance company and Cornerstone Hospice. Each insurance company has its own unique system. Under federal law, Hospice is required to bill the patient for copayments and/or deductibles that are not covered by his/her insurance. The patient will receive a statement from Hospice showing the balance after the insurance company has paid. For convenience, we accept cash, check, Master Card, VISA, American Express and Discover.

Sliding Fee Scale

Those patients who have no insurance and do not qualify for Medicaid may be asked to pay for Hospice services on a sliding fee scale. The Hospice social worker or financial liaison will assist the patient and families with completing a request for financial assistance.

Social Security Information

Social Security Benefits

It is important that you consider Social Security benefits, if applicable, as a significant part of your estate. Social Security is more than a program for retired people. It helps people of all ages in many ways. For example, it can help support your family in the event of your death and pay you benefits if you become severely disabled.

Please remember that Social Security benefits are not paid automatically. They must be applied for. In order to apply, your survivor must complete and submit several documents to the Social Security Administration office within a specific period of time.

Documents Required:

- Proof of Death (several are needed)
- Deceased’s Social Security Card
- Marriage Certificate (copy is acceptable)
- Deceased’s Birth Certificate
- Applicant’s Birth Certificate
- Minor Children’s Birth Certificates
- Proof of Disabled Child (over 18 years of age)
- Funeral-Receipted Invoice of Deceased
- Record of Income for Preceding Years
- Proof of Termination of Any Previous Marriage

(Additional documents may be required.)

FOR MORE INFORMATION You should contact the Social Security office nearest you for complete benefit information and guidance. Refer to your telephone directory for the number or address of the nearest Social Security office. For questions or comments but not completed forms, you can also write to:

Social Security Administration
6401 Security Boulevard, Baltimore, MD 21235
1.800.772.1213
Your earnings and benefit estimate

To obtain an estimate of what your future Social Security benefits will be and how you can qualify for them, call your local Social Security office. Or, go to www.socialsecurity.gov/onlineservices.

You may complete the following online:
• Apply for benefits
• Appeal a decision
• Find out if you qualify for benefits
• Estimate your future benefits
• Block electronic access to your information
• Get a password
• If you have a password, check your information and benefits, etc.

ONLINE STEP-BY-STEP GUIDE
1. Visit Social Security Online Services website (related link 1 below), choose the benefits you want to apply.
2. As instructed, answer the application questions, when finished, click “Apply Now”.
3. To answer these questions, you may be asked to provide your date of birth, Social Security number, direct deposit numbers, total earnings last year, expected earnings this year, the name and address of your employers in the past 3 years and so on.
4. Print the application, sign on it, then mail it with the documents required to the address given by Social Security Administration.

RELATED LINKS
• Social Security Online Services: http://www.socialsecurity.gov/onlineservices/
• Social Security Administration: http://www.ssa.gov

The site also provides hours of operations and a locator for an office nearest you. You may also choose a language other than English, review Frequently Asked Questions, and see related links concerning benefits, among other items of information.

Veterans Benefits Information

If you are an honorably discharged veteran and have completed the required period of duty, you or your family may be entitled to a wide range of benefits, including burial benefits. Like Social Security benefits, Veterans benefits are not paid automatically; they must be applied for to be paid.

When filing for Veterans benefits, the following documents will be required:
• Veteran’s Death Certificate
• Veteran’s Marriage Certificate (copy)
• Birth Certificates of Veteran’s Minor Children
• Veteran’s Discharge Papers
• Receipt of Veteran’s Funeral Bill (itemized)

Because these benefits and allowances are changed by the Veterans Administration and the U.S. Congress from time to time, you are encouraged to check with your local or regional Veterans Administration office for current information on benefits and procedures. Call the Department of Veterans Affairs in Washington, D.C., or write:
Department of Veterans Affairs
810 Vermont Avenue
N.W. Washington, D.C. 20420

REIMBURSEMENT OF BURIAL EXPENSES A burial and funeral expense allowance will be paid for deceased veterans who were, at the time of death, entitled to receive pension or compensation, or would have been entitled to receive compensation but for the receipt of military retired pay. Eligibility is also established when death occurs in a VA facility or in a contract nursing home to which the deceased was properly admitted.

In addition, a plot of interment allowance will be paid if the requirements for the burial allowance are met, or if the deceased was discharged from active duty because of disability which was incurred or aggravated in line of duty. The plot allowance is not payable if the veteran is buried in a national cemetery. If the veteran is buried without charge for the cost of a plot or interment in a State-owned cemetery, used solely for burying persons eligible for burial in a national cemetery, the plot allowance may be paid to the State.
BURIAL ALLOWANCE FOR SERVICE-CONNECTED DEATH For veterans who die of a service-connected disability, a burial allowance may be paid in lieu of other burial benefits. Claim for non-service connected burial allowance must be filed within two years after burial or cremation. There is no time limit for filing a claim for service-connected benefits.

BURIAL FLAG An American flag will be issued to drape the casket of an eligible veteran who was discharged under conditions other than dishonorable. A flag will also be issued for a veteran who is missing in action and is later presumed dead. After the funeral service, the flag may be given to the next of kin or close friend or associate of the deceased. Flags are issued at any VA office, VA national cemetery and most local post offices.

INTERMENT IN NATIONAL CEMETERIES The interment of an eligible deceased veteran of wartime or peacetime service will be authorized in any cemetery in which grave space is available. Deceased spouses, minor children and certain adult dependent children of an eligible veteran are also eligible. There is no charge for a grave in a national cemetery. A headstone or marker with appropriate inscription for each decedent buried in a grave will be provided by the Government. Application for burial can be made by the next of kin or the funeral director, only at the time of death of a veteran (or that of an eligible dependent) by contacting the director of the national cemetery in which the burial is desired.

TRANSPORTATION OF DECEASED VETERAN TO A NATIONAL CEMETERY The transportation cost of a deceased veteran for burial in a national cemetery may be paid when the veteran dies of a service-connected disability; or the veteran was in receipt of (but for the receipt of retired pay or disability pension would have been entitled to) disability compensation. Payment shall not exceed the cost of transportation to the national cemetery nearest the veteran’s last place of residence in which burial space is available.

HEADSTONE OR MARKER A Government monument will be furnished upon request, and at no charge, to mark the grave of an eligible veteran buried in a national, military post or base, state veterans’ or private cemetery. The grave of a veteran must be unmarked for a monument to be furnished at Government expense.

Cornerstone Foundation

Cornerstone Hospice is dedicated to providing exemplary care to anyone facing a life-limiting condition, regardless of their ability to pay. Reimbursements from Medicare, Medicaid, and private insurance often fall short of fiscally meeting the needs of the families in our care. The financial shortfall is supported by the generosity of the community. Cornerstone Hospice Foundation is administered exclusively to provide the philanthropic link between donors and patient care. As a non-profit 501(c) 3 tax exempt organization, all gifts qualify as charitable contributions as provided by law.

Cornerstone Hospice Foundation exists to:

- Develop philanthropic resources to enhance, support, and complement the mission of Cornerstone operations.
- Disburse gift funds in strict accordance with the wishes of the donor.
- Provide a permanent fiduciary organization responsible for professional administration and management of permanent endowment funds and trust gifts.

How you can help the Foundation

GIFTS IN LIEU OF FLOWERS AND GIFTS IN MEMORY OR HONOR OF A LOVED ONE Memorial gifts help light the way for Hospice patients while honoring your loved one or friend. A distinctive acknowledgment letter is sent to the loved ones’ family and a thank you letter is sent to the donor.

PERMANENT RECOGNITION Choose from Bricks of Love, Tree of Life, or other naming opportunities at each of the Hospice houses and inpatient units. Contact us about additional information on other naming opportunities for rooms, chapels or future Hospice buildings.

SENDING GIFTS without a tribute is a great way to support the Cornerstone Mission.

UNITED WAY Designate Cornerstone Hospice for employment campaigns.

MATCHING GIFTS Let us know if your employers offer this program to magnify the impact of your gift.
FURNITURE AND VEHICLE DONATIONS Our website has information on vehicle donations. Call our office for furniture and home furnishing donations.

DONATE YOUR TIME Cornerstone has hundreds of volunteers who help with all manner of tasks, from office help to pet therapy to spending time with patients. You can also volunteer in the community or local advisory board to help attract gifts and donations.

ORGANIZATIONS AND COMMUNITIES You may be part of an organization or live in a community that holds special events for charitable causes. Cornerstone Hospice is blessed to have many such groups throughout our coverage area that host fundraising events on our behalf. If you know of such an opportunity or want more information on how your community can help please reach out to us.

LAKE COUNTY’S WOMEN FOR HOSPICE is a group of over 300 women who hold monthly luncheons, operate the Hope Chest (an upscale resale shop in downtown Mount Dora), organize special events and more. In its 20-year history, the group has raised over $2 million in donations. If you are not in Lake County, consider starting a similar group in your county.

Planned gifts and estate planning

“Planned giving” refers to the method of using tax laws as well as strategic, estate, and financial planning techniques to maximize an individual’s asset for themselves, their heirs, and/or their favorite charities.

In general, planned gifts take the form of bequests, gift annuities or a variety of charitable trust documents. Planned gifts enable donors to support specific programs or services at Cornerstone. The Foundation staff stands ready to work with individuals and their advisors in making Cornerstone Hospice a designated beneficiary in their estate plan. Where there is a will, there is a way you can help leave a legacy. Please call our office and we can explain these options:

- Life income agreement
- Bequests through a will or estate plan
- Gifts of securities, real estate, and other appreciated property
- Beneficiary designations on life insurance, retirement plans and bank accounts.

Visit csh.giftlegacy.com and scroll down to the Wills icon to start planning your free will, or contact us to receive a free Wills & Trust guide.

Trusted Advisors

Families facing end-of-life situations sometimes need the help of an attorney, financial planner, or other professional. If you need help with drafting a Last Will and Testament, Durable Power of Attorney, Living Will or other document and are in need of an advisor, the Foundation has a group of Trusted Advisors whose names can be found on our website.

These advisors are also available to answer questions about probate, insurance claims, and investment options. You will receive timely advice and guidance that is in your best interest at a reasonable fee.

Contact the Foundation

Cornerstone Hospice Foundation
2445 Lane Park Road
Tavares, FL 32778
888.728.6234 // 352.343.1341
info@cshospice.org
Personal Data

When dealing with a terminal illness, providing vital information in advance can ease the pain and confusion of loved ones left behind. The following type of information is important. Your Hospice social worker can assist you and your loved ones in compiling this information.

Name_________________________________________ Date ________________________________

Address __________________________________________________________________________

City ___________________________ State ___________ Zip _______________________

Phone (__________) ____________________________

Birthplace __________________________________________________________________________ Date of Birth _________________

City ___________________________ State ______________

Occupation ______________________________________________________

Employed by (or Retired From) __________________________________________________________

Single __________ Married __________ Widowed __________ Divorced __________

Spouse of ______________________________________________________

In city since___________________________ Citizen of ____________________________

Father’s Name ____________________________

Birthplace: City_________________________ State ______________

Mother’s Maiden Name ____________________________

Birthplace: City_________________________ State ______________

Are you a veteran? __________________________________

If answered “Yes”: Rank __________________ Date Enlisted ______________________________

Branch of Service ___________________________ “C” No. ________________________________

Location of Discharge Papers ______________________________________________________

For help or advice in settling my affairs, and in making arrangements for the future, please notify ____________________________

PLEASE REMOVE “PERSONAL DATA” FROM THIS HANDBOOK, STORE IN A SAFE PLACE, AND NOTIFY A FAMILY MEMBER OF WHERE IT IS STORED.
Will/Living Will

I (have) (do not have) a living will. (See special information on Living Will / Health Care Surrogate / Durable Power of Attorney in the Planning Ahead section of this handbook.)

Copies are kept ____________________________________________________________

I (have) (have not) made a will.
If a will has been made, who is executor? _______________________________________

**NOTE**: An updated will, drawn in this state, is important. See your attorney.

A copy is kept ________________________________________________________________

My attorney is __________________________ My bank is ___________________________

Additional bank(s) __________________________________________________________

___________________________________________________________________________

Real estate owned ____________________________________________________________

Location of deeds ____________________________________________________________

Other property (boat, autos, etc.) and location of registrations ______________________

___________________________________________________________________________

My investment broker is ______________________________________________________

My insurance advisor is ______________________________________________________

Location of insurance policies _________________________________________________

Location of deed to cemetery lot or crypt _______________________________________

Notify following companies __________________________________________________

Memorial Trust No. _______________________________________________________________________

Relatives and friends who should be notified. Include relationship, name, address, phone:

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

**NOTE**: Are the listed beneficiaries and executors on policies, trusts, etc. current?
The Family

You can do anything—but you can’t do everything. Cornerstone Hospice recognizes the substantial physical, emotional and economic demands placed on caregivers as they attempt to deliver care for their loved one and also meet their own personal needs. That extra stress puts one at risk for fatigue, emotional distress, and physical illness. It is important to take care of oneself during this time of caregiving. For this reason, your team will be giving attention to the needs of the caregiver, as well as the patient during their visits. They will answer your questions and provide expert advice, set up respite care if needed, and make referrals to community resources.

Our teams offer encouragement and anticipatory guidance throughout the caregiving experience. Nurses will monitor the patient for changes and interpret their meaning for you, so that you can feel secure and supported in your role. The amount of care that we provide to patients and caregivers is individualized and is spelled out in the plan of care. Let your Hospice care team know what your needs are, and we will design a plan just for you and your loved one.

Patient Centered Care

Death is the great unknown mystery of life. There are many beliefs and fears, rituals and rites, perceptions and misconceptions. The only two things we know for sure are that dying is a natural part of life that we will all experience, and that no one really knows what it is like.

The question is sometimes asked, “How do I die?” Hospice will help you answer the question, “How do I live fully until I die?” Each death, like each life, is quite different—unique to that person in time and space.

We at Cornerstone Hospice practice “patient centered care.” We want to get to know you and all your wishes and dreams that may impact how we provide your care. We want to know the big things that you need, but also the little things that make each moment special. The feeling of a cold puppy nose against dry skin. The warmth of a grandchild snuggling close. The smell of freshly baked cookies, even if you don’t feel like eating any. We will always ask “what will make you happy? How can we make your life become more wonderful, not just less horrible?” We are here for you and we will work hard to make your ‘winter days’ as warm as they can be.
Here is a quick summary of things that you can do to ensure that you are caring for yourself as carefully as you care for your loved one:

- **REST.** When you are under stress, even simple activities can be tiring. Plan frequent short periods of rest to clear your mind and allow yourself to rejuvenate.
- **PACE YOURSELF.** Many things need to be done, but not everything has to be done right away.
- **EXERCISE.** Walks or moderate exercise reduces stress and renews energy
- **LAUGH.** Laughter truly is the best medicine. Enjoy a funny show, read funny books, and laugh out loud together.
- **ASK FOR HELP.** Many are willing to help or just give you their friendship. Don’t hesitate to allow others the joy of being needed. Friends, relatives or Hospice volunteers can help with meals, shopping or just acting as a sitter for a bit to allow you to get out.
- **STAY CONNECTED.** It is important to maintain social connections and normalize your life. Going to church, joining in the Bridge Club or just visiting with your neighbor are all good ways to avoid isolation. Do the things you love to do.
- **TAKE IT ONE DAY AT A TIME.** Or sometimes one minute at a time. Just focus on the here and now. What can you do right now? The rest will take care of itself.
- **TALK ABOUT IT.** It isn’t helpful to bottle up your worries or your sadness. Talking about these things releases their burden and helps you gain a better perspective.
- **TAKE NOTES.** We recommend you keep a small notebook divided into two columns. In one column, write down questions for your team and in the second column record their answers. No question is too trivial. Asking questions isn’t a sign of failure, but a sign of good common sense. The more you know and understand about this journey, the better you will be able to cope. But at any time, if you feel overwhelmed, notify someone on your team immediately!

“The job is not to straighten each other out, but to help each other up.”
—Neva Coyle

**The Interdisciplinary Team**

The needs of the Hospice patient and his/her family are multifaceted and complex. No one person could possibly meet all the needs that arise. Therefore, we utilize a multi-discipline approach to care for the various needs of the patient and caregiver. The interdisciplinary team is made up of the Team Physician or Advanced Registered Nurse Practitioner, Nurses, Social Workers, Hospice Aides, Chaplains, Volunteer Coordinator and Bereavement Counselor. A brief description of their individual roles is provided at the very beginning of this handbook. Available to consult as needed are dietary counselors, as well as occupational and physical therapists. Each team member contributes information that is gathered from talking to the patient and family. The team collaborates to design a customized plan of care.

The plan of care is a living and breathing document that identifies the goals, needs and wishes that the patient and family have identified as important to them. It is individualized, and based on the patient’s and family’s definition of quality of life. The team discusses and develops interventions and plans, with the patient’s approval, to accomplish the stated goals. The plan of care is continually updated to meet changing needs. The patient and family are the center of all we do. We ask for direction in identifying pain and symptom management needs and psychosocial and spiritual goals for the patient and family.
Communication

Communication with your team

With each difficult issue that arises, the Hospice team works to minimize the impact. As the disease advances and the body changes, the priorities of the patient or family may change. Little things are not so little. We want to know what is important to you, so let us know of any changes in your desires or needs. It is important to develop a trusting relationship with your interdisciplinary team members so you can clearly communicate your needs and goals. We are sworn to uphold confidentiality and privacy, so you can be open and honest. Talk to us and we will listen. We want to help you.

Patient and family communication

Hospice patients and families often keep secrets to protect each other from suffering and sadness. While the intention may be good, open and honest communication is essential at the end of life. Here is a scenario:

Judy doesn’t want her father, John, to know that the visiting nurse is from Hospice because she is afraid that he will give up hope.

Meanwhile, John knows he is very sick, but he pretends to be okay in the presence of Judy because he doesn’t want her to worry.

Both are acting with the best of intentions, but openness and honesty would bring this family so much more peace.

The effort it takes to hide the truth is very tiring and produces more stress in the already tense circumstances of terminal illness. This can actually prevent meaningful, honest communication that could bring your family closer together during this challenging but precious time.

A daughter who can talk to her father about his life and be a reflective advocate achieves so much more. Through reflection and thinking together out loud, the patient comes to terms with his life, including all of its ups and its downs. He recognizes that this life was his own, lived the way he chose. His accomplishments are celebrated with his loving family. He sees that his life—and his death—matter. What most Hospice patients want is to feel that their life counted; they want to experience love of self and others and have a sense of completion in their relationships with family and friends. Through open communication, one gains new insights, experiences, personal growth and inner healing.

What needs to be said

Research has shown that there are things that need to be said at the end of life that benefit both the patient and the family. Having heartfelt communication seems to foster a more peaceful death for the patient and an easier grieving period for the family. These short phrases are a meaningful closure to a life lived not perfectly, but well. Expressing appreciation, love, and forgiveness seems to validate one’s relationships and brings closure to all.

So what do we say and how do we say it? Just simply saying, “I love you,” “Thank you,” “I’m sorry,” “I forgive you,” “Please forgive me,” “I will always remember...”, is all there is to it.

Say it once or say it often. Say it simply and with sincerity. Write it. Sing it. Be creative or be simple. These phrases are also helpful when facilitating conversations between children and the patient. If you need assistance in opening up the door to this level of expression, your team can help. We can act as an intermediary, or as the host of a family meeting. Tell us if you need us, we are happy to help.
Friend and visitor communication

Friends are an important part of our lives, and we want to encourage the patient and caregiver to maintain those social relationships. Sometimes friends want to help, but they don't know what to do. Sometimes caregivers refuse their offers to help. Through the act of giving, friends are able to express love and devotion. Allow your friends to give of their time and heart. Accept their help and incorporate them into the circle of caring. They can act as sitters, run errands or just be part of your support system by keeping you company.

Social interactions are encouraged as long as your loved one feels well enough to receive guests, but it may fall to the caregiver to monitor the patient’s tolerance. Visitors can be tiring and some may overstay their welcome without realizing it. It is okay to announce the end of a visit, if you pick up cues that your loved one is tired. It may even be a good idea to ask visitors ahead of time to limit their visits.

Sometimes friends or relatives may temporarily forget that they are in a sick room. They may speak on topics not appropriate to the patient’s sacred space or just talk too loudly. It is okay to be the “keeper of peace.” It will fall to the caregiver to be aware of the patient’s non-verbal cues, especially toward the end, when the patient is not verbal. Watch for restlessness, purposeless movements or other signs of anxiety. You may even want to establish an alternating schedule, limiting visitors to two at a time. If you need assistance in dealing with friends or relatives, your interdisciplinary team can help you.

“A good friend is a connection to life—a tie to the past, a road to the future, the key to sanity in a totally insane world.”

— Lois Wyse
Unknown Territory

A nurse was visiting a patient who had terminal breast cancer. While having a light conversation about the weather, the patient suddenly stopped, looked the nurse straight in the eye, and said, “You have to help me. I’ve never died before.”

This season of life is unknown territory for each one who goes through it. Our team will be here to walk this journey with you. We will work to keep you and your loved one feeling well. We will help you and your family to create and recreate lovely moments and memories and to say what needs to be said to one another. We will work with your family to give them the support and knowledge that they will need to cope with the changes that lie ahead. And when your journey is at an end, we will still be here, offering bereavement support and comfort to your spouse and children.

Fear of the unknown for the family

The Hospice team will teach you what to expect and how to manage patient symptoms that may arise. This booklet will educate you on how to prepare and how to respond to the changes in bodily processes that will occur as death nears. In addition, you should rely on your team to walk you through each new situation or symptom. They are trained and knowledgeable about what is normal and they will relieve your mind and give you confidence. It is important that you feel competent and confident in your abilities as you meet the needs of your loved one.

It is not unusual to experience emotional or spiritual conflict during this time of stress. Rely on the social worker and spiritual counselor for support and comfort. They can set up family meetings, make suggestions to improve communication and also be a sounding board to help sort out your own thoughts.

Fear of the unknown for the patient

While many patients come to accept their terminal diagnosis, they may still fear the process of dying. Fears of the unknown are common at the end of life— it is the great unknown, after all. Our nurses, social workers, and spiritual counselors can talk with you, understand your concerns and work with you to minimize your anxiety. While no one has all the answers, it will help to have a heart-to-heart talk and share your thoughts and feelings with an empathetic professional.

“T’wonder where I am going after I die.” Be assured that it is normal to have these worries, no matter your beliefs. Our non-denominational spiritual care chaplains can help you explore your thoughts and fears and provide emotional support as you work toward your own conclusion. We meet you where you are in your spiritual or denominational belief system. We will never preach to you; we only want to support your spiritual journey. Feel free to request a visit from your spiritual counselor to discuss your spiritual needs.

Fear of suffering

Palliative care is an approach that improves the quality of life for patients and their families. It is about providing comfort and living well. Palliative care is defined by the World Health Organization as “the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Through this approach, Hospice care can eliminate unnecessary suffering.

However, suffering is a part of being human.

Through experiencing losses and enduring the trials and challenges of life, we adjust and grow as human beings. We become more compassionate of others and their suffering. Through coming face to face with forces larger than ourselves, we come to terms with loss. Suffering unites caregivers and care receivers. Families of Hospice patients have expressed feeling closer to their loved one during the last weeks and days of their lives through the intimacy of shared suffering. Through this shared suffering, healing

“Worry does not empty tomorrow of its sorrow; it empties today of its strength.”

— Corrie Ten Boom
happens. The meaning of healing in this context is that a person has finished his business, said his goodbyes and reached his end-of-life goals.

**Loss of independence**

One of the hardest things to lose, as your health is failing, is your independence. Being unable to care for yourself is a humbling experience. Needing someone else to help you bathe, eat, or use the toilet is a challenging strike to your ego.

Yet, what an expression of love and devotion from your caregiver! Caregivers often say that the ability to help their loved one at this time is very rewarding and helps them feel needed. We endeavor to give you information to help you through the maze of treatment decisions from giving “as needed” medications to providing nutritional support to completing legal documents. We want you to continually engage with your team to develop plans and for the interpretation and monitoring of the decline and dying process.

The more you understand this journey, the better you will be able to cope. But if at any time you feel overwhelmed, notify someone on your team immediately.

**Time and space perception**

During the end of their lives, it may seem that our loved ones have drifted away. They may no longer respond to us. Even if they are conscious and able to verbalize, they seem to have little desire to interact with us. We recognize that they have lost interest in those things they used to hold dear; their favorite team, friends or visitors.

Do not be disheartened. It is normal for our loved ones to withdraw in preparation for what lies ahead. In addition, their sense of time and space changes and they may be in the present or in the past. They may even talk to relatives who have passed, as if they were there in the room. While this may be very disconcerting, it can be handled in a very matter of fact way. “No, Dad, I don’t see Aunt Martha, but I believe that you see her. What is she saying to you?” Validate their perceptions without lying to them. What these hallucinations mean is difficult to say, but they happen too frequently to discount them. As long as they are not distressing to the patient, we do not intervene.

**Spiritual support**

It is expected that patients and families may feel the need for extra spiritual support or guidance at this time. Hospice chaplains are non-denominational and are trained to help meet your individual spiritual needs. They allow the patient and family to set the agenda for their visits and offer an opportunity to think out loud about life.

The chaplain acts as a reflective advocate and assists the patient and family in working through their burdensome issues or questions. In addition, our chaplains will help connect you to a specific faith leader in your community, if you choose.

Our Hospice goal is to assist patient and families to find physical, emotional and spiritual comfort and peace. Please feel free to notify your team if you would like a chaplain visit. Rest assured that we will follow your lead rather than direct your journey.

— Elizabeth Kubler-Ross

“People are like stained glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within.”
Creating a sacred space

Sacred dying is a new paradigm of care and presence, changing the way our society experiences death and dying by returning the sacred to the act of dying. At the time of death, each person must face the extraordinary journey from this life to the next.

Rather than our society’s model of death as failure or abandonment of medical care, sacred dying recognizes death as a sacred transition. Honoring religious and faith traditions, cultural practices, and personal spirituality, all people deserve an end of life experience that is filled with honor, presence, prayer and support.

Think of how special space is made in everyday life. We clean, we bring nice things, we add flowers and items of beauty. Sacred space is not all that different. The intent must be there, and the physical surroundings must be properly arranged.

The room speaks many things. Is it antiseptic and cold? Is it institutional and devoid of anyone’s personality? Is there something of the dying persons present? Who are the visitors? What is their emotional state? All of these things make a difference as a person is dying.

It is easy to create sacred surroundings. There are some simple ways to make a space, sacred. When a person is dying, he/she is usually in a bedroom or a health care setting like a hospital or nursing home. You cannot change that, so use it to your advantage. Use the bed as the center of a circle, making it a place of comfort and nurturing. Think of a baby’s nursery; the brand new room parents prepare for their baby is centered on the crib. The bed is warm and inviting, meant to take care of the child and provide a safe place to sleep. The bed of a dying person needs to hold the patient safely in the same way.

Dying is sometimes a painful experience. The body is not only shutting down, it is also fighting disease. The bed needs to be a place of protection and warmth, at the center of the sacred space. If a hospital bed is used, try to make it comfortable and clean. Bring in extra pillows, blankets that are soft, warm and familiar. Think of a person’s bed at home and try to recreate it.

Sacred space should be devoid of clutter and chaos. Dying is not a time when people feel in control. The physical surroundings tend to reflect that feeling of helplessness. Straightening the surroundings can help make those around feel better about the circumstances; cleaning up can also give a sense of purpose and helpfulness. But be aware of what clutter is and what is there by design. For example, a picture may be placed where the patient can see it or a glass of water placed where the patient can reach it.

Many times the air in the room is musty or stale. Opening windows or letting in fresh air is very helpful. An air purifier or ionizer can help balance the air. Rituals can be done or prayers said when opening the window. The symbol of air and wind, as the divine spirit, is part of many faith traditions.

After you have physically cleaned and opened up the room, wash your hands again. Once the physical work is done, it is now time to bring more spiritual work. Remember, as you walk into a room, to look for ways you can bring in the divine presence. And then, as you proceed, make each step intentional. Say a prayer as you close off the area around the bed. Talk to the dying person. Sing as you clean and straighten. As you light candles (turn them on), ask a blessing. As you hang pictures, ask for the divine to watch over the room. Each intention verbalized, adds power and strength to the holy space.
Using the senses

The senses present multiple opportunities to create sacred space. We can use sight and smell and sound to create surroundings that are not only conducive to comfort and ease in letting go but also provide feelings of holiness.

SOUNDS

- Lean in toward the person dying and speak lovingly. Even in a “chant” that is spoken softly can be helpful. Example: “You are loved, you are loved, you are loved.”
- Figuring out how to use the time left with a dying loved one can be frustrating. Read out loud. If the patient is asleep or unconscious, sitting and staring at the end of the bed is not an enjoyable pastime. Scripture readings can be helpful if one has found that comforting in life; however, stories don’t have to be particularly serious or religious. In fact, reading from children’s books gives people a sense of bedtime.
- Music is an extremely powerful sound that affects us in many ways. In fact, music is said to be able to reach places inside of us that words cannot touch. It can also distract and irritate. Choose music that is soft and calming, music that can help the person let go of pain and discomfort. Watch the patient’s face and body for reactions to the type of music being played.
- It is thought that the sounds of nature can be relaxing and sometimes restorative. Don’t hesitate to play sounds of nature like babbling brooks, waves of the sea, anything that can help someone sink into a blissful state, where life is quiet and soothing.
- Silence is a powerful experience. There is an art to knowing when someone needs to talk and when silence is best. Sounds are often difficult for people who are ill; noise can feel magnified and grating. Even loud voices can be irritating. Most religious traditions have strong practices of keeping silent. Silence presents a setting that allows people to calm themselves and move into deep prayer and meditation.
- In general, it is good to keep conversation to quiet reflections or to words of encouragement and love. It is nice to hear a daughter quietly tell her mother about the children and how well they are doing, assuring her that they will grow up to be good and loving people. Sometimes we forget and have conversations as if the dying person were not in the same room. For example, adult children talking about dividing up an estate or complaining what a nuisance it is to sit in the hospital room all day long. These are not appropriate conversations to have in the patient’s room. Sacred space deserves sacred words.
SIGHT

- When you go into a religious sanctuary, everything around you reflects the sacred. It may be a beautiful stained glass window or an artistic mural. When a person is dying, the sacred can be brought to the room visually. Why not put something beautiful into the patient's line of vision? Statues, holy pictures, or small icons can be held in the palm of the hand. Devotional objects, such as prayer beads, a rosary, or a prayer, can reassure people. Just having these items present can be reassuring even if the person is not physically capable of praying or meditating. Photographs of family members can also be comforting and some patients may want to hold them.

- Altars can be made with the help of the family. Over a stack of books or shoe boxes, for instance you can drape a soft colored curtain, towel, scarf, sheets, etc. to make a “sacred table.” Bring things that reflect the personality of the dying person such as pebbles, twigs, flowers, leaves, herbs that help with relaxation (such as lavender, rosemary, or chamomile), favorite poems or prayers, pictures of animals, etc. Friends and family can add objects that are meaningful to the patient. This can be a good project for children.

- Light and darkness are themes that come up often in many faith traditions, moving toward the light represents coming closer to the divine. Darkness can be frightening; it holds images of fear or the unknown. Battery operated candles in a dark room do more than just provide light. Flickering candle light makes people feel peaceful and safe.

SMELL

Sometimes sensitivity to odors can be acute. Certain scents can evoke memories for people. It can be even bring on physical pain or nausea. Scents are often used in religious ceremonies, for example incense is used in Russian Orthodox churches as well as Buddhist temples and sage and other herbs are used in Native American and earth traditions. Smells are powerful, but require extra sensitivity near the end of life.

If you can, ask about smells. What does the patient like? What have they used in the past? Here are some ways to incorporate scents into the sacred space:

- Incense is a low-maintenance option
- Scented candles (on warmers to avoid open flames)
- Flowers
- Sweet spices. In the Jewish tradition, at the end of Sabbath, a container of sweet spices is passed around the room to remind people of the sweetness and pungency of life. It usually contains fresh whole cinnamon, cloves, allspice, nutmeg, and other spices like ginger and mace.
- Aromatherapy. The scents used for relaxation or letting go are chamomile, lavender, rose and geranium.
- Smells from home and childhood. People respond most strongly to baking (bread, cakes and cookies), simmering soups, stews, newly mowed grass or Christmas trees
- Scents of loved ones. Use articles of clothing with a trace of perfume or pillows or blankets with a light fragrance.
Leaving a legacy

What is important right now? Chances are, those things you used to think were most important are no longer at the top of your list. Perspectives have changed. Sharing a life review with your family or your Hospice team can prove invaluable in identifying your lifelong accomplishments and affirming your values. This legacy of a life well lived is a story that is worth sharing. Spend time looking at old photographs, reading old letters, talking about the vacations that you took and the people you knew. You may want to keep a notebook or draw pictures of things that you hold dear. Perhaps you would like to record your thoughts or ask a volunteer to make notes as you talk. Anything is possible. What is important to you?

This is your life; not a perfect life, but one worthy of note. In the words of Dame Cicely Saunders, the founder of modern day Hospice, “You matter because you are you. You matter to the last moment of life, and we will do all we can, not only to help you die peacefully, but also to live until you die.” So live ferociously, live well—not in spite of death, but because of it. We’re here to help.

“We are all just walking each other home.”

— Ram Dass
Symptoms

Caring for someone at this part of their life can be quite a challenge. Here are some tips and suggestions to help with the physical care for possible symptoms:

Abdominal swelling

Sometimes fluids can accumulate in the abdomen, causing a swollen appearance. There are many reasons why this could occur and it may not be preventable. The medical term is “ascities” - the cause is related to the body systems shutting down. The causes could include tumors blocking drainage; the heart may not be working well enough for the body, fluids or blood vessels may be damaged and not allowing the blood to flow through appropriately. This causes the fluids to seep from the lymphatic system or blood vessels into the abdomen. Sometimes the accumulation of fluid in the abdomen causes pain, difficulty breathing, difficulty sleeping, loss of appetite and/or nausea and vomiting.

You can work with your Hospice team to discuss if restricting or decreasing salt/sodium and monosodium glutamate (MSG) would help. Call Cornerstone Hospice when you first notice the swelling or if/when you experience pain, difficulty breathing, have problems with urination, have anorexia lasting a day or more or begin having nausea and vomiting. Some measures of comfort might be elevating the head of the bed, wearing loose clothing and taking the prescribed medications. Your Hospice MD and nurse might discuss possible draining options.

Ambulating and transferring

Along with weakness and disease progression, the ability to walk safely and transfer from a chair to bed becomes increasingly difficult. It’s okay to stay in bed if that’s where you are the most comfortable. Saving energy for the times you want to go somewhere or do something important might be a good plan for you. Falls are our biggest concern for you. Some ways to avoid falls would be to sit on the side of the bed for a minute before standing.

Use of assistive devices might become a need to keep you safe from falling and causing an injury. Wheelchairs can help save energy if it seems too much to walk or if you have shortness of breath with walking. Walkers are helpful if your legs do not feel secure when you are walking. Safety should be first in your mind so that you do not fall or injure yourself.

Use of side rails on the side of your bed can help you with sitting up. Non-slip bathmats in the shower or bathtub can be helpful along with a safety rail on the walls to help you stand from sitting. Look around your house to make your environment safe. Look for electrical wires across the floor, loose rugs or spilled water. Scatter rugs can also be problematic if you are having difficulty lifting your feet.

Sometimes you might feel isolated from the rest of the family so it’s okay to consider moving your bed or allowing Cornerstone to order a hospital bed for you in the main part of your home so that you can remain a part of your family. We also have bedside commodes for those times when the bathroom is too far away. Your Hospice team wants you to be able to do what you want to for as long as you can. Talk with them if you develop difficulty with walking or start needing help getting out of a chair or off the toilet. We are here to assist you any way we can.

Anxiety

Anxiety and restlessness may be caused by a number of factors. When the body is shutting down it produces a feeling that something is wrong. This may be attributed to the slowing of circulation causing a decrease in the amount to oxygen to the brain. It could also be a sign of discomfort or physical pain.

Sometimes emotional pain or a feeling of unresolved issues could be the reason for the anxiety. It is best to involve your Hospice team to help determine what the cause is.

Some signs of anxiety would be difficulty solving problems, excitability, muscle tension, trembling, nightmares, difficulty breathing, tense feelings, numbness or feeling like you are out of control, or that something is just not right.

Some helpful tips would be to continue with the prescribed medication routine, to help the person resolve the problem. Promote a calm environment, play soft music, try to read something inspirational. Sometimes just holding hands and giving reassurance is all that is needed. Be sure to involve the whole Hospice team to help. The Social Worker and Chaplin are great resources to help the person address and resolve issues. Volunteers can read to the person, sit by their side, pray with the person. The nurse and physician can help to prescribe medications to help the person relax and rest. It is important to know that it is okay to feel sad and be afraid, seeking help through your support system and your Hospice team could help.
Bathing

Bathing helps reduce odors and chances of infection. When it becomes harder to get to the bathroom to perform this task, it can become overwhelming. Some ways to help when you can still get to the bathroom are to place a stool by the sink to help preserve energy. If you can manage to get into the shower or tub, a shower bench or chair might be helpful, along with grab bars and a hand held shower head. These are just suggestions to think about to promote independence and to ensure safety. When the bathroom is no longer manageable, someone may have to help give a sponge bath. This does provide the same benefit. As the skin becomes more delicate it may hurt at times. Gentle movements, mild soaps and lotion can promote comfort. Fresh clean clothes and bedding, adding relaxing music and a calming approach can add to the experience. The Hospice nurse and or home Hospice aide can be helpful in showing ways to prepare the bed linens to help with soiling, repositioning, and bathing the person. Using a folded sheet under the trunk of the patient’s body to help move them up and down in bed or “roll” them onto their side may be helpful. Sometimes it’s helpful to have a hospital bed in your home to help with repositioning, lowering and raising the head. This also helps preserve your back if you are bending over or reaching across. Changing their position in bed at least every two hours can reduce the risk of a sore developing. Other equipment can be helpful like a bedside table, wash basin, disposable pads, and side railings for the bed. Consult with your team to find the best items to help you out. If the person has difficulty with dressing into clean clothes, and have become mostly bedbound, you can cut the back of the shirt or nightgown and lay over the top of the person. We may have to use adult diapers at this time as well. Working with your team as new conditions develop is the best way to be able to manage the patient’s needs.

Bed sores or pressure sores

Pressure Sores/Bed Sores develop when the oxygen flow to an area of the body is stopped and the tissue in that area starts to deteriorate. Causes include poor nutrition, being in one position for an extended time, tumors that break through the skin, incontinence of stool or urine, or rubbing of the sheets on fragile skin. These are painful, but treatment options are available. The treatments vary, depending on the size, depth and cause of the sore. Signs to watch for include red areas on the skin that do not go away when the pressure is removed, and discomfort or pain in the bony areas such as hips, heels, elbows, spine, sides of knees, ears, back of the head and sacrum (bone at base of spine). Turning and repositioning is the best practice for prevention of these sores. Some ways to prevent them are to observe the skin on the bony areas at least once a day. Avoid hot water and use mild cleansing agents that minimize irritation or skin dryness. Use moisturizers on dry areas. When sitting change position every half hour to an hour. If bedbound, change positions at least every two hours, using pillows to help position if needed, especially on heels and buttocks. It is helpful to massage the area around the sore. Try to keep the fitted bed sheet pulled tight to prevent wrinkles and work with your Hospice team on the proper way to reposition or lift the patient up in the bed. Bed Sores are not always indicative of lack of care. Prevention is the best treatment so proper amount of fluids and diet. If eating becomes a problem, drinking high-calorie liquids, like milkshakes or nutritional supplements may help. Eat or encourage eating foods high in protein. Some foods that could help promote healing are citrus fruits, green leafy vegetables, grains, meat, fish and eggs. The Hospice team will be able to implement the best options. It is best to inform your team at first sign of skin breakdown, so that we might be able to prevent the wound from getting worse.

Blood in the urine

Blood can appear in the urine when bleeding occurs in the urinary system. Some causes may be urinary tract infections, kidney or bladder stones, injury to the urinary tract, tumor growth or defects in blood clotting. Symptoms include pink or red urine, pain when urinating, clots or bloody mucous strands in the urine. This can be frightening if there is a large amount or a sudden onset of bleeding. It can also become painful if you are passing blood clots. Lower back pain in the flank area is sometimes a sign of a kidney stone or an injury to the kidney. Some preventative tips would be cleaning the genital area by washing from front to back and, urinate when you feel the urge, drink as much fluid as possible (one quart every 8 hours unless otherwise instructed). Call your Hospice team when you first notice any blood, a pink coloration or cloudiness or a foul smell.
in your urine. If you have a Foley catheter and urine stops all together, it could be a blood clot blocking the passageway and should be addressed immediately.

**Confusion**

Confusion is a common symptom in an ill person and can be caused by many things. It is difficult to prevent but it’s important to look for the cause. Causes include severe pain, fever, low blood sugar, alcohol withdrawal, and lack of oxygen to the brain, a urinary tract infection, too much calcium in the blood stream, tumor spread, or a side effect from narcotic medications. Confusion can appear as drowsiness, being easily startled or frightened, rambling speech and/or inappropriate behavior or hallucinations. If English is not the language you spoke when you were growing up, you may revert back to the language of your childhood.

It is best to inform your Hospice team if you notice that you are experiencing confusion. Tell us when this is happening and how frequently. Confusion can fluctuate from lesser to greater severity. Your Hospice team might be able to identify the cause and help work on the treatment.

Some things you can do that might help with confusion are to let people know if you are hard of hearing because this can sometimes be interpreted as confusion. Keep a night light on in your bedroom or bathroom. When you are alone play soft soothing music or any music you like. Keep familiar things around you, like a favorite picture, a quilt, clock or calendar.

For the caregiver, always tell the patient who you are, use gentle touching and always face the patient while you are talking to them. Talk slowly and in short sentences. Frequently try to orient the patient to the day, time and place. Explain everything you are doing. Try to act in a calm manner. Call your Hospice team at the very first signs of confusion or aggressive behavior.

**Constipation**

Constipation is difficult or infrequent bowel movements. This is very common when your normal diet, fluid intake and activity level are changed. Medications such as narcotics also greatly slow down the way waste moves through the intestinal system. Signs to look for are no bowel movements in at least three days, a bloating feeling, pressure or sense of fullness in the rectum, rectal pain with a bowel movement and/or nausea and vomiting. The bowel continues to produce waste even when you are not eating, so it’s really important to keep track of your bowel movements.

Prevention is key to help with constipation. Prevention measures include eating foods high in fiber such as whole grain cereals, nuts and seeds, dried fruits, beans, peas, raw fruits and vegetables. Sprinkle unprocessed bran on food. Drink plenty of fluids, drink hot or warm liquids such as hot lemon water or warm prune juice can be options. Be as active as possible for as long as possible. Avoid regular use of enemas, and follow the bowel control plan suggested by your Cornerstone team.

The Bristol Stool Chart (above) is a tool that you can use to communicate with your nurse or Hospice aide about your bowel movements. Just pick a number that most closely resembles your stool.

Moving your bowels is an extremely private act. Having to perform this in front of others, having to discuss it, or having someone help can be embarrassing but if left untreated it can lead to an obstruction. Sitting on a bedpan can be more difficult than sitting on a commode or toilet. Fear of constipation may cause you to stop taking pain medications or medications to treat other symptoms but please talk to your Hospice team to come up with the right plan of care. (continued)
A WORD ABOUT BEDPANS: No one is comfortable using one. Use a towel on the back side for padding. Keep the bedpan and commode clean and available at the bedside. Try to help the patient into a sitting position when using the bedpan by raising the head of bed if they are in a hospital bed. Give the patient privacy. Wash the rectal area after each stool; wash your hands and the patient’s after use.

Cough
A chronic cough can be caused by the disease process, from infection or allergies. Coughing might cause other symptoms such as; a sore throat, poor appetite, insomnia, vomiting, dizziness, muscle pain, fracture of a rib and/or exhaustion.

Talk with your Cornerstone team to discuss some treatment options. Some helpful things to do would be to use a room humidifier or steam inhalation. You may need to keep your head elevated for comfort. Drinking lots of fluids can help keep the throat moisturized; sucking on hard candy or lozenges can be helpful. Let Cornerstone know if the cough becomes persistent so we can work together for a treatment that’s right for you.

Dehydration
Dehydration can occur when fluids are excreted through urination, perspiration, diarrhea, vomitus and drainage. Sometimes confusion occurs as well as headaches, dry skin, dry mouth, cracked lips, sore throat, fever and malaise (severe weakness). Prevention would be to drink as much fluid as you can to try to replace the fluid lost. Gatorade can be helpful as well. Plan a fluid intake goal for the day and try to stick to it. Try to drink the greatest amount of fluid in the morning so that your sleep will be uninterrupted. Use Chapstick on your lips, and moisturizer on your skin.

Dehydration is treated differently at end of life versus early on in the illness. Work with your Hospice team to help with ways to overcome dehydration.

Depression
It is normal to feel sadness and discouragement when you are facing the challenges of an illness. The sadness can be overwhelming, causing difficulty with focusing, facing day to day activities and putting energy into anything. Medications and treatments can also be the culprit to depression so please discuss this with your Hospice team.

Loss of appetite, difficulty sleeping; only wanting to sleep and difficulty concentrating or engaging in conversations can be some of the signs. Try to focus on positives instead of negatives. Spending time with people who you enjoy being with, trying to remain active in your day, and openly discussing your thoughts and feelings will help you to cope.

Suggestions to stop the negative thoughts include listening to music, looking at art, guided imagery, get up and move, distract yourself, ask family and friends to visit or share happy memories and stories. Be sure to communicate your Hospice team about feelings of depression. Your team is skilled in addressing this challenge through the above interventions, visits from your chaplain, social worker and even the use of medications if needed.

Diarrhea
Diarrhea is less common at the end of life, although medications or altered diets can cause this. Infections in debilitated patients are also a common cause. Keep a record of the number and amount of stools and discuss this problem with your nurse. You can utilize the Bristol Stool Chart to help you in discussing these symptoms. It may help to eliminate milk products, carbonated beverages or gas producing foods such as broccoli or cabbage. Encourage clear fluid intake (Gatorade, water or broth) to minimize dehydration.

Difficulty breathing or shortness of breath
Breathing patterns change as the body shuts down. It is normal if you feel anxious, afraid, or weak. Near the end of life, breathing may become shallow and rapid or there may be times when there are seconds between each breath. It can be difficult to watch, but it’s not uncomfortable to the person. This is the normal response to that body system weakening. Try not to hold your breath if you are at the bedside watching. Just breathe.

Some helpful tips are to use a fan or open a window if appropriate. Changing positions may help, such as elevating the head of bed slightly, prop head up with a pillow, or turning to the side could help. If the mouth becomes dry from the frequent mouth breathing, mouth care and moistening of the lips may be useful. Try to remain calm. Inhale through your nose and exhale through pursed lips for twice as long as it took to inhale. Try to rest adequately
between activities and try to conserve energy. Place chairs in places so that you can rest adequately on the way. Ask your nurse if a wheel chair or walker with a seat might be helpful to help conserve energy. Avoid gas producing foods that can cause bloating.

Your Hospice team can help by prescribing medications that can minimize excessive secretions and help ease breathing and promote comfort. Please refer to Oxygen Safety (40) if you have oxygen in your home.

**Difficulty swallowing**

This is called dysphagia. Dysphagia can be caused by disease progression, side effects from treatments like chemotherapy and radiation, from an infection or from weakness. It is seen in patients with Alzheimer's Dementia, or a CVA (stroke). Indications include drooling, gagging, choking, regurgitation of food, excessive saliva or no saliva at all. Sometimes you may notice white patches on the inside of throat or mouth.

Tips that can help include sitting up after eating for at least an hour, trying to keep mouth moist by drinking liquids, and taking pills with water. Good mouth care is essential. Sour or spicy foods can increase salivation; sweet foods can decrease salivation. Eat small meals with soft foods. Use products like ‘thick it’ in liquids. Blend or puree some foods if it’s easier to swallow soft foods.

Experiment with warm versus cold foods and stick to the ones that are easier to swallow. Talk with your Hospice team to help with liquid medications, or ability to crush some medications. Always call Cornerstone when you first notice difficulty with swallowing so we can help plan with you.

**Dizziness**

This is a sensation of whirling or feeling like you could fall. Often it is described as a feeling of lightheadedness, like you are going to faint, difficulty with balance or a sense that everything is spinning.

Some considerations would be to change positions slowly, and move from lying to sitting in stages. Avoid bending over or quick movements. Sometimes weakness and dehydration can cause dizziness. Blood pressure changes sometimes occur if your normal activity has changed. The Cornerstone team can help determine the cause and work on your plan of care with you. Call your team if you feel that you are at risk for falling, have a loss of consciousness, or experience a headache with the dizziness.

**Dry mouth**

This can be caused by multiple factors usually the reduction in amount of saliva in the mouth. Some of the causes are medications, mouth breathing, and treatments like chemotherapy and radiation therapy. Some of the symptoms of dry mouth are your tongue sticks to the roof of your mouth, thick saliva that stays attached to your lips when you open your mouth. You may experience excessive thirst when you awaken or notice changes when/if you are using oxygen for breathing. Often people complain of having a cotton ball in their mouth.

Some suggestions to help with dry mouth would be increase the amount of fluid intake, avoid extremely hot or cold foods, and avoid smoking and alcoholic beverages. Sucking on lemon drops or chewing gum might be helpful. Rinsing your mouth can sometimes help moisten, you can use Chap Stick to keep your lips moist. If you are using oxygen for long periods of time, a moisturizer may need to be added by your team to help with the dryness. Toothettes can also be used to keep the mouth moist.

Your Cornerstone team can work with you on a plan of care to help if the medications are causing drying or your fluids are to be restricted.

**Fever or body temperature changes**

Everyone has a normal body temperature that is usually around 98.6 degrees F. Fever occurs when the body temperature reaches 100.5 degrees F by mouth. Fevers are related to infection, inflammation, drug reactions, tumor growth or unknown origins. Fevers can also be accompanied with shaking and chills, feeling tired, confusion, achy, sore throat, rash or blotchy redness, feeling cool, and having a headache.

Try to drink as much fluid as possible (Gatorade is best). Rest, use a fan or air conditioner, cover with a sheet, and change clothes and bedding if they become wet. Ask for help with transferring or walking if you are weak. If you are immuno-compromised by your disease process, make sure you wash your hands frequently, ask visitors who are ill to wait to visit, and don’t share drinking glasses, eating utensils or towels. Avoid crowded places if you know your blood counts are compromised.

Alert your team if you experience any signs of fever, if you do not make urine for 6 to 8 hours, if you have chest pain or trouble breathing, if you have shaking and chills and/or a cough. (continued)
COOLNESS  As your loved one becomes weaker, his or her circulation decreases. You may notice that extremities feel cool to the touch and skin color may change. The hands and feet may become purplish, and the knees, ankles and elbows may look blotchy. The person may appear pale and have a bluish cast around the lips and under the fingernails. To help, you can use a warm blanket, but not an electric blanket. Continue to gently reposition the person or provide “gentle” massage. Discuss this change with your Cornerstone Team to help give you ways to keep the patient comfortable.

Hemoptysis (blood in sputum)

Hemoptysis is the spitting up of blood from the lungs or bronchial tubes. This happens for various reasons. This can be frightening for the patient and the caregiver. Causes are associated with various diseases. The Hospice nurse and physician can alert you if this might be a possibility for you. If you notice streaks or specks of blood in your sputum or if you develop a cough and spit up blood, call Cornerstone right away so we can start the treatment process quickly. The typical form of hemoptysis is blood tinged sputum.

Major bleeds are rare, but if this is a risk for you, you might consider having red or brown towels available to absorb the blood. If you are taking a medication to thin your blood (such as Warafin or Coumadin), ask your Hospice team if you should stop taking it.

Hiccups

A hiccup is a spasm of the diaphragm (the main muscle used in breathing). They can be from an irritation of the nerve that controls the diaphragm or from excess air in the stomach.

Hiccups can be frustrating. Try to avoid large meals and eating while hiccuping. Sometimes drinking peppermint water can help to reduce gastric distension.

Call your Hospice if the hiccups last for more than a day, if your stomach appears swollen or if you are experiencing difficulty breathing.

Indigestion

Indigestion is painful digestion. Indigestion can be accompanied by belching, discomfort when you lie down flat and radiating pain in your back region. Avoid coffee and alcohol, fatty fried foods, spicy foods, or foods that tend to give you indigestion. Eat more frequent small meals through the day. Try sitting up for one to two hours after you eat to aid in digestion. Be cautious about taking antacids as they may negatively affect other medications. Check with your Cornerstone nurse and physician to ensure your antacid is the correct one to take.

Insomnia

Insomnia is the inability to sleep when you expect sleep to occur. You may have problems with falling asleep or staying asleep or both. Oftentimes it’s caused by uncontrolled pain, dyspnea or a “mind that races.” Insomnia can aggravate pain and other symptoms.

Make sure that your pain is being managed to allow you to relax enough to sleep. Avoid naps during the day if possible. Seek help or counseling to deal with your worries, fears, and anxieties during the day hours. Discuss your nightmares and dreams. Continue to do your pre-bed rituals to prepare for sleep. Listen to soothing music or use relaxation therapy. Try to read or engage in a relaxing activity until drowsiness ensues.

Work with your care team to develop ways to help with your sleep. A sleep medication may need to be prescribed to help you rest.

Itching

Itching can be caused by a multitude of reasons including medications, disease process, dehydration, rashes, reactions to treatments and dry skin.

Some ways to help are adding oil to the bath water and using warm water instead of hot water. Try patting your skin dry instead of rubbing. Avoid alcohol based products and use lotions to moisturize the skin. Try to drink plenty of water. Avoid scratching because it can stimulate the release of histamine which makes it worse. Keep your nails short and clean. Change bed sheets often. Wear loose clothing made of soft fabrics. Keep room cool.

Call your Hospice team if you scratch your skin open, if itching lasts more than 2 days, if a rash or hives develop, or if you notice your skin turning yellow and the whites of your eyes appear yellow.

Jaundice

Jaundice is a yellowish hue to the skin or whites of your eyes. The discoloration is caused by a condition where the normal processing of bile is compromised. Usually, it occurs in liver or gall bladder disease. It is usually an unpreventable process. The most common
side effect of jaundice is itching. Sometimes your urine can turn a deep orange color and you might notice white or clay colored stools. Call your Cornerstone care team to discuss what is happening. Follow the interventions listed under “Itching” to help with alleviating the itching sensation.

**Medicines**

Your physician will prescribe the medicines that are needed to control pain and other symptoms. Pain is usually controlled by oral medications instead of injections. Working with your team can help find the best combination of medications to promote comfort.

When narcotics are prescribed, some common fears are the following:

- That frequent use will lead to addiction.
- That frequent use will result in the patient sleeping all the time or being incoherent.
- That, if the medication is used too early, it won’t be effective later.

Our experience, supported by scientific literature, indicates that none of these fears are accurate. The patient can remain alert while pain is controlled by the following:

- Adjusting the amount and type(s) of medication according to the severity and type of the patient’s pain.
- Giving the medication regularly around the clock to prevent pain from recurring.
- By maintaining a constant level of medication in the body, the patient’s pain can be controlled while enabling the patient to remain alert.

Side effects may include the following:

- Temporary sedation is experienced while the body adjusts. When the pain is brought under control, the patient may also need to catch up on rest. If sedation persists for more than three days, talk to your nurse about adjusting the dose.
- Constipation is a frequent side effect of pain medication. Giving the patient prune juice and bran may relieve symptoms; however, laxatives may also be necessary.
- Nausea may be prevented by eating a few crackers before taking the medication. If symptoms persist, medications for nausea are available.

If the patient has difficulty swallowing, most medications are available in liquid or rectal suppository form.

In all cases, Cornerstone will work closely with the patient’s physician to control pain.

**Comfort kit**

Upon admission, your admission nurse will get a physician’s order to have a Comfort Kit delivered to your home, if warranted. The Comfort Kit is a sealed box with a small amount of medicine inside to provide symptom management in emergent situations.

The following instructions will be given to you regarding the Comfort Kit:

- When the comfort kit is delivered to your home via courier, place it immediately in your refrigerator
- **DO NOT OPEN THE KIT.** Leave it sealed.
- Please call your Hospice team FIRST if you are experiencing any uncontrolled symptoms.
- Only open the kit as instructed by your nurse or physician.

**Muscle spasms**

Muscle Spasms are involuntary contractions that are usually painful, followed by and soreness of the muscle. It can be caused from staying in bed or one position for too long, too much potassium, too little calcium or too much phosphorus in your diet. Try changing positions frequently if able, and adding foods high in calcium and potassium (such as dairy foods and dried peas, bananas or beans). Another suggestion is to exercise legs while in bed by bending and straightening often.

Call your Hospice care team if cramping continues for more than four hours, and if attempts you’ve made to relieve the pain are unsuccessful, we will work with you to find ways to avoid muscle spasms.

**Nausea and vomiting**

Nausea and vomiting are stimulated by the brain’s nausea centers. Triggers include smells, medications, treatments, motion, disease process and more.

Some factors that can exacerbate nausea and vomiting are a change in eating habits, eating fried foods, dairy products, acidic foods and juices and uncontrolled pain. Try to eat foods like dry toast, peppermint, saltine crackers, yogurt and salty foods. Breathe deeply and swallow. Try foods at room temperature or cold. Try distraction, relaxation techniques and get fresh air. Eat foods high in protein when less nauseous. Try rinsing your mouth frequently and applying a cool damp cloth on your forehead, on your neck and wrists.

If you are in bed, lie on your side to prevent
choking. Wait at least 2 hours after vomiting before taking anything by mouth. Start with ice chips, frozen juice chips, popsicles and raspberry or peppermint tea.

Call your Hospice team if you notice blood or the appearance of coffee grounds in the vomit. Contact your team if you are vomiting more than 3 times in an hour or are vomiting for more than 3 hours, if you are unable to take your medications, or you think you choked on some of the vomited material. If you are unable to eat any food in 24 hours or have increased stomach pains with the nausea and vomiting, your team will help you develop a plan to keep you comfortable and pain free.

Pain

Pain is whatever the experiencing person says it is. Our role is to work with you to find the right combination of pain medication to adequately alleviate the pain. Some people have discomfort with any movement; some just hurt everywhere but can't describe it. Everyone is different. The best thing to do is work with the Hospice team by reporting as much as you can about the pain. Not all people experience pain at the end of their life and that’s great, but we do not want anyone to have pain.

Some find it helpful to keep a journal or log of where the pain is, was there anything that may have precipitated it, what times that the medication was taken and if it helped. Learning how to describe the quality of pain such as burning, stabbing, throbbing etc. will help the team to find the right medications to help alleviate the pain for you. We can use tools to help rate the pain level and your team can work on this with you. The most common tool is numbers from zero to ten, ten being the worst pain imaginable.

Pain medication works best when given on a regular schedule. If the pain becomes out of control, it takes longer to get relief. Usually it takes 30 to 45 minutes for it to absorb into the blood stream, so regular intervals are the best way to keep pain under control.

Pain medication slows down everything in the digestive system and can cause constipation. It is essential that we work to stay on top of this. There are remedies we can prescribe so that constipation does not cause more pain.

Sometimes pain can cause nausea, lack of energy and decreased appetite, so treating the pain is one of the most important roles for all of us.

When a person is nearing the end of their life and unable to tell us about his/her pain level, we need to watch for signs of discomfort like groaning, moaning and facial grimacing. Even when a person is unable to verbally communicate, if he/she exhibits signs of discomfort you still need to use pain medication. The Hospice nurse can demonstrate how to give medication under the tongue or other routes if they are unable to swallow.

PAIN RATING SCALE Your nurse will explain how to use a pain rating scale. Very simply, you will frequently be asked to rate your pain on a scale of zero to ten with zero being no pain and ten being the worst pain you can imagine. Above is a picture of the pain rating scale.
Poor appetite

Poor appetite is when you are eating less than you normally do. It's called anorexia. It can be the result of chemical changes caused by the disease. Sometimes it can be corrected and sometimes not. At the end of life, one may develop a sore mouth, difficulty with swallowing, abdominal discomfort, fullness when eating a small amount, nausea, constipation, or weakness.

Eat as much as you want, when you want to. Try to eat foods higher in protein to give you some strength. Drink fluids between meals rather than with food.

You may want to sprinkle more sugar or salt on your foods as taste buds may be altered. Work with your Hospice team to come up with ways to add calories to your meals.

Food and showing love go hand and hand in our culture. Sometimes family members feel guilty if you are not eating like you used to. Therefore, it sometimes can be harder on family than you. Consult with your physician, as there may be some medications that could improve your appetite.

Sore mouth

Inside of your mouth are rapid growing cells that can be affected by some of the treatments you received. Chemotherapy and some medications slow down the growth of healthy cells in the mouth. Symptoms may include redness on the tongue, white patches on the gums or on the inside of the mouth, feeling like there is cotton in your mouth, and difficulty swallowing.

Some preventive treatment could be to rinse your mouth often, brush teeth after meals with a soft toothbrush, increase the amount of fluids you drink, avoid alcohol based mouthwashes or glycerin mouth swabs. Use Chap Stick or a moisturizing lip balm to prevent cracking lips. Smoking and alcoholic beverages may irritate the mouth. An infection called thrush which exhibits as a white patchy appearance on gums or sides of mouth usually requires an antifungal medication. You should try to complete the entire treatment.

Call Cornerstone if you develop a fever of greater than 100.5 degrees F, if you notice the white patches in your mouth, or if you have difficulty swallowing and experience pain in your mouth.

Seizures

Seizures can look scary. They are a convulsive movement of muscles and the loss of consciousness followed by confusion or sleepiness. They are caused by changes in the normal impulses to and from the brain. Causes of seizures include a history of epilepsy, a high fever, and injury to the head, tumor growth or an infection.

Seizures may be preceded by a cry or moan followed by loss of consciousness, sudden inability to control bladder or bowel, jerky movements of legs and arms, and eyes rolling or staring into space. Sometimes you might see some frothy white substance from the mouth.

As a witness of a seizure, the best thing to do is provide safety for the patient and try to prevent injury. Stay by his/her side and wait until the seizure is over. Have someone call the Cornerstone team to give you some support and help to take the next steps needed for prevention.

Some preventative measures are to take seizure medications, being careful not to skip any doses. If you have a history of seizures, pad any areas with a towel or blanket to protect from injury. If you have a seizure history, identify what your triggers might be (such as bright and flashing lights) and eliminate them from your environment.

Swelling

Swelling, also called edema, is simply an accumulation of fluid in the tissues. This can be very painful and has many causes; such as, malnutrition, failure of the heart, kidneys, liver or tumor growth obstructing the circulation of the veins or lymph system. Usually fluid accumulates in the legs if you are sitting in one position for a long period, or in the hands, or lower back if in bed. Beware of rings, socks, and watches, name bands, etc. that can cause skin breakdown if they are too tight.

It is best to maintain activity for as long as possible. Elevate your legs if you are sitting most of the time. Use pillows to help prop up legs, arms during times when you are in bed. Try to eat a balanced diet, avoiding sodium if possible.

Swollen skin can break down easily so good skin care is very important. Work with your Hospice care team to help if any signs of swelling occur.
Unconsciousness

Unconsciousness means that the patient is no longer able to respond. Causes include the following: lack of oxygen to the brain, tumor spread to the brain, changes in metabolic conditions or impending death.

Unconsciousness can occur slowly over time. It is a coma-like state and can last for days to weeks. Usually, there are no signs of discomfort. It is a normal progression from an increase in lethargy or weakness, lack of participation in conversations, mental confusion or changes, up to total failure to respond.

It is thought that patients can still hear you and feel your touch. They can no longer eat or arouse to swallow liquids. It is best to moisten the lips and mouth with toothettes. Please let your Cornerstone team know of the change in condition so that they can help you through this phase.

Urinary incontinence

Urinary incontinence can occur toward the end of life. It may be related to weakness, being unaware of bodily functions, or advancing disease processes. It can be very distressing for the patient to lose control of bodily functions and can also be a strain on caregivers. Our goal is to support the patient and caregiver with interventions that help them to manage incontinence in a least distressful manner.

The nurse can order a bedside commode so elimination can be managed quickly and conveniently. Adult briefs can be worn so that patient maintains independence. Disposable pads can be placed in the bed and in some cases a urinary catheter can be inserted. Your nurse can provide you with advice and intervention; just let your nurse know what your needs are.

Toward the end of life, urinary output commonly diminishes, with the urine becoming concentrated, odorous, and dark in color. The urine is very acidic and it is especially important to keep the skin clean and dry to avoid skin breakdowns and decubitus ulcers.

The above interventions will help, but changing of pads or briefs as needed is the ultimate answer.

The nurse might suggest inserting a catheter to help keep the patient’s skin dry. You will need to be shown these easy steps in caring for the catheter:

- Wash your hands before and after working with the catheter, if the catheter is not draining, i.e., if there is no urine in the bag, do the following:
- Check for kinks in the tubing. Be sure the bag is lower than the level of the patient and that the patient is not lying on the tubing. Call your nurse if the problem continues. Empty the bag into a bedpan or another container at least once a day, unclamp, drain into a container and clamp again.
- Check the area around where the catheter enters the body for leaks and wash it daily as follows: using a clean cloth, wash with warm water and soap. Rinse with water. Dry.
- Call the nurse if you have any questions or problems.
Challenges

Infection prevention

When caring for your loved one, please remember to prevent the spread of colds, viruses, and infections. The best way to prevent the spread of infections is hand washing. Hands should be cleansed before and after providing care, touching dressings, urine, stool, wounds, or after sneezing, coughing, or after touching used tissues. Wash your hands after using the restroom and before and after eating. Remind visitors to wash their hands before they touch your loved one. Help your loved one to clean his/her hands as needed.

The use of foams or gels for hand cleaning maybe used in place of hand washing. Try not to allow friends or visitors who are may be ill to visit your loved one. If they do visit, have them keep their distance, wash their hands, and refrain from sneezing or coughing near the patient. If your loved one has used needles or lancets, they need to be disposed of in a hard puncture resistant container so that others are not stuck by them. Your nurse can help you to have an appropriate container and will be able to provide a needle box to use when needed. Also, if there are dressings or pads or other disposable items saturated with blood, ask your Hospice Nurse to provide you with an approved red bag/container for their disposal. Household bleach diluted with 10 parts water to 1 part bleach can be used to clean any surfaces that have been contaminated with blood. Wipe down hard surfaces in the home with disinfectant wipes frequently. Cell phones and remote controls should be wiped down as well. The Hospice Nurse will remove any red bag/special containers from your home as needed. Gloves, diapers, and disposable bed pads maybe placed in your regular trash unless they are saturated with blood. If you have any question related to infection control, please ask your nurse.

Medication use and safety

• Keep a list of all medications that you take. This includes prescription medications, medications you buy without a prescription, vitamins and herbal supplements.
• Store all medication in their original clearly marked containers.
• Take medications exactly as directed by your physician or nurse practitioner.
• Notify your physician, nurse practitioner or Hospice nurse promptly if you notice a new symptom or side effect from your medication.
• Discuss with your physician and nurse why you are taking a medication, the results you should expect from taking the medication and possible side effects.
• Stick with the recommended treatment plan.
• If you think a change needs to be made to a medication, talk to your Hospice nurse or doctor first. Do not try to adjust your dosage yourself or skip medications.
• Never give or sell your prescription medication to somebody else. Your medication was prescribed only for you.
• Keep all medication out of the reach of children, pets or others who may be harmed.
• Avoid drinking alcohol while taking prescription medications.
• Medication that is no longer needed or that has expired should be disposed of safely.

Your Cornerstone Hospice nurse will discuss the safe disposal of medication and destroy Hospice medication no longer needed in accordance with Cornerstone policy and procedure.

“Coming together is a beginning, staying together is progress, and working together is success”

—Henry Ford
Oxygen use and safety

NO SMOKING BY ANYONE IN THE HOME WHILE OXYGEN IS IN USE.

- Post “No Smoking” sign in home.
- Do not store oxygen cylinders near heat sources.
- Do not use flammable or petroleum-based products (Vaseline® ChapStick®, aerosol spray such as hair spray) near oxygen.
- Do not change the liter flow that was ordered by your doctor.
- Do not leave oxygen equipment on when not in use.
- Do not store oxygen in a confined space.
- Do not attempt to repair the oxygen equipment.
- Do not touch the metal fittings of liquid oxygen units.
- Do not use extension cords or multiple outlet adapters with oxygen equipment.
- Handle oxygen equipment carefully.
- Store oxygen cylinders securely and in a well-ventilated area.

Call Cornerstone Hospice with any problems or concerns you may have about your oxygen.

Safety in the home

- Keep hallways and paths clear. Scatter rugs can slide and plastic mats can come loose and cause falls.
- Remove any small rugs on the top or bottom of stairs.
- Be sure all rugs are in good repair and any curling or torn/frayed areas are anchored. Duct tape works well.
- Have non-slip strips or a rubber mat in the tub or shower.
- Use a bedside commode when needed.
- Set water temperature no higher than 120°.
- Turn on lights when entering a room or using stairs.
- Be sure all rooms have a clear path without hazards or objects over which to stumble.
- Small pets can pose a trip hazard.
- Have telephone and emergency numbers available.
- Keep a fire extinguisher or at least a large box of baking soda in your kitchen.
- Night lights can safely guide you into a room or down a hall.
- Keep a flashlight handy in case of a power outage.
- Identify emergency exits to be used in case of fire.
- Smoke alarms save lives. Is one present? Is it functional?
- Be certain that electrical cords and outlets are in good repair; i.e., cords not frayed, outlets not overloaded.
- Is the environment safe for effective oxygen use?
- Excessively long oxygen tubing can pose a trip hazard.
- NEVER, NEVER, SMOKE IN BED OR WHEN OXYGEN IS IN USE.
- Develop an emergency plan to use in the event of a disaster or regional emergency. Cornerstone staff will review your disaster plan with you. Please report any changes to them.
Disaster Planning

In case of a disaster, such as a storm, hurricane or other emergency, we strongly encourage all patients and their families to have an emergency plan.

Plans should include:

- Evacuation Plan
- Alternative Residence
- Emergency Items and Foods
- Medical Supplies and Medications
- System to notify family and friends of your location during an evacuation

Cornerstone Hospice will attempt to contact all patients in the event of a Hurricane Watch. Contact your Hospice team as soon as possible after storm warnings are issued if you are not at your home. Verify with the Hospice team whether you will evacuate to the shelter or another location (family/friend’s home).

Persons who should evacuate are those who:

- Live in a mobile home or designated flood zone.
- Receive medications or fluids by infusion (IV fluids or medications).
- Are dependent on supplemental oxygen (oxygen concentrators or portable oxygen tanks).
- Are receiving tube feedings.
- Are dependent on any type of medical equipment operating on electricity.

If you are in one of the above categories, evacuation is recommended whether you live in a specified evacuation zone or not. The reason for this is to ensure your medications, IV fluids and other needed services and supplies will be available to you. Any Cornerstone Hospice patient may evacuate to the special needs shelters (SNS) rather than a community shelter close to their home. If an emergency occurs, Hospice staff will not be able to make visits. Roads may be inaccessible and phone lines may be down. Your electricity may be off; therefore, oxygen and other equipment will not continue to function.

It is extremely important to take needed supplies or special dietary items with you. There will be limited supplies and no comfort items at the shelter. Hospital beds are not available at any shelter. Cots will be available for patients. Patients should be accompanied by one caregiver, who should bring his/her own personal items, including special dietary or medical needs.

Take the following supplies with you (as applicable):

- All medications from home; an additional supply may be available at the SNS if you receive your medications from Cornerstone Hospice.
- Patient Family Handbook and any additional written information or personal health records regarding your care; i.e., advance directives, Do Not Resuscitate Order, etc.
- Personal hygiene items and change of clothing
- Important documents (in an envelope marked with your name and phone number)
- An adequate supply of bedding, pillows and blankets.
- Non-perishable food, special food needs and drinking water
- Dressing supplies, diapers, pads and other needed hygiene items
- Formula for tube feedings, feeding pump
- Nebulizer and supplies
- Portable oxygen tank – do not take your concentrator
- Suction machine and supplies
- IV pole, bags of infusion fluids, medications for infusion, infusion supplies (red tool box, irrigation sets)

**Pets may not be allowed at shelters. Check for information.**

It is important to remember this will be a busy time for all involved. Do not wait until the last minute to prepare. Please contact Cornerstone Hospice as soon as possible for assistance if no one from Cornerstone has contacted you.

Remember it is urgent you do not “put off” going to the shelter until the last minute. The county vehicles that will be evacuating patients who have no transportation will be very busy and need to plan their pickups to make the best use of their time. Emergency vehicles will not be on the road once sustained winds reach 40 mph. Emergency number 9-1-1 will not respond after winds reach 40 mph. Please evacuate when you are advised. There may not be a second chance to leave.

While we realize it may be a great inconvenience to evacuate your home, this is the only way we can assure your continued care and supply of medications or other needed supplies. The Cornerstone Hospice staff will continue with your care while you are at the special needs shelter, if allowed.
Advice for those who are not in one of the above evacuation categories and for those who choose not to evacuate:

- Place your electric bed in a comfortable position. If there is a power failure, the manual crank will be the only way to change the position of the bed.
- Use your oxygen concentrator as long as power is available. Use portable oxygen sparingly, as no additional tanks can be delivered during the storm.
- Stock up needed food and supplies. You should plan for at least a seven-day supply.
- If you receive medications from Hospice, they will be delivered to you before the storm. If you receive medications from another source, your nurse will ask your doctor to order an extra supply before the storm. Arrange to pick them up in your usual manner.
- Contact Cornerstone Hospice staff as soon as possible to let them know your location and condition.
- If help is needed and Hospice staff cannot be reached, attempt to call local law enforcement agencies.
- For true emergencies, call 911. However, once sustained winds reach 40 mph, they will not be able to respond until the storm has subsided. In the event of death, attempt to call Cornerstone Hospice, the police department or the funeral home. Communication systems may fail or not work properly.

You may not be able to contact Hospice or other assistance during the storm or immediately after. Hospice staff will attempt to get to you as soon as possible after the storm.

County Emergency Numbers

**HARDEE COUNTY**
Hardee County Sheriff’s Office
863.773.0304

**HIGHLANDS COUNTY**
Emergency Operations Center
863.385.1112

**LAKE COUNTY**
Emergency Management
352.343.9420

**ORANGE COUNTY**
Emergency Management
407.836.9140 // 407.836.3111

**OSCEOLA COUNTY**
Emergency Management
407.742.9000

**POLK COUNTY**
Emergency Management
863.534.0321

**SUMTER COUNTY**
Emergency Management
352.569.6000

*See Addendum C: “Information for Hospice Patients” prepared by the Florida Department of Elder Affairs.*
When The Time Comes
What the journey can look like

We are often asked the question, “How much time do I have?” The truth is that we do not know. What we can share with you is an estimated time frame based on how your body is responding to the disease process. These characteristics do not happen to everyone but they are measurements for you just to try to prepare yourself or your family for what is happening. Please review the symptoms and challenges section of handbook to give you an idea of what to expect.

1–3 MONTHS REMAIN:
• Eating and drinking less than normal
• Sleeping more hours in a day
• Withdrawal from what’s happening
• Less ability to concentrate
• Limited communication

1–3 WEEKS REMAIN:
• Physical changes — lower blood pressure, pulse either faster than normal, or lower than normal, body temperature fluctuates from fever to cold
• May notice perspiration or a clamminess to skin
• Skin color — flushes (red hue) with fever or blue tinges of extremities with coldness
• Agitation or restlessness
• Talking to unseen people
• Increased confusion
• Loses sense of night and day
• Picking at blankets, clothes, tubes and drains, if present
• Decreased appetite, not wanting or desiring food
• Respirations become irregular
• Noted increased congestion
• Sleeping a deep sleep and not easily awakened
• Complaining of body being tired or heavy

DAYS OR HOURS REMAIN:
• Intensified symptoms mentioned in weeks 1-3
• A brief surge of energy
• Glassy eyes or half opened eyes
• Irregular breathing, periods of no breathing at all, then deep breaths
• Restlessness or no activity at all
• Noticed purplish or blotchy knees, ankles, feet and hands
• Blue fingers
• Weak Pulse
• Very limited amount of urine produced
• Incontinence

MINUTES REMAIN
• Long pauses between respirations
• Hands and toes are cool to touch
• Unable to arouse
• Eye may be half open, may be open but glazed over; occasionally a tear will flow out, known as the “last tear”
• May have a lot of secretions and foaming around mouth
• May have a loud noise with the respirations
• Very limp body
• Coloration of face and hand changes
This phase can last for hours to days. It is the transitional stage of dying. The care is different at this point. The patient may exhibit some or all of the following changes: sleeping most of the time, talking to people that have previously died, skin color changes, breathing changes, congestion, body temperature changes, glassy look in the eyes, perspiration, and picking at clothing. These are all normal responses as the body systems start to shut down. It is difficult for anyone to tell you the exact time, because it is not known.

Please let your Cornerstone team know so that they can assist you through this period of time, offer support and guide you through this process. Comfort packs are available to help with any symptom management needs that may arise. Our goal is to promote comfort during this time.

The last moments

We know that the sense of hearing remains until the very end, even if the patient cannot respond. So it is important to continue talking in a loving and gentle way. Remember that the patient is aware of your presence and is often comforted by just knowing that you are there. You can read to or sing to the patient or sit quietly and hold his/her hand.

The sense of touch is also present. Sometimes patients want to be touched and appreciate a back rub, but other times it may be too much stimulation. Rely on non-verbal cues to determine if the patient wishes to be patted, rubbed or held.

“Seeing death as the end of life is like seeing the horizon as the end of the ocean.”
—David Searls
Passing

The vigil before the patient passes may be short or long. There is no way to know for sure. Your nurse can act as a guide and teach concerning some signs that may occur prior to death. However, each patient will die in his/her own time. The patient may linger when all signs indicate imminent death. Someone who lived a private life will often prefer to die privately. Someone who was outgoing and who preferred to be around people may pass surrounded by family. Either scenario can be considered a good death. More than once family members have reported that they were all there, but as soon as they left the room to get coffee, the patient passed.

This can cause some guilt for some family members, but unnecessarily so. Patients seem to choose their own time, so there is no need to feel guilty. It is always a good thing to say reassuring words when you leave the bedside.

At the moment of death, there is no breathing or heartbeat. There is no response to you. The eyes may open partially, the mouth may open and sometimes there is loss of bowel and bladder control. This is all part of the final process. The experience of this moment may still take you by surprise, but it is not an emergent situation, and there is no need to call 911 services at this time. Please call your Cornerstone number to let us know, we can help you with the rest.

Some things you can do at this time are to play special music, tell stories, light a candle, and follow through with some of your spiritual rituals that are important to your family.

Confirmation of death

A nurse will come to confirm the death and to provide support for you and your family. The nurse will remove any drains or tubes that are present and offer to bathe and prepare the body if you desire. We can call the funeral home if you wish, and will notify the physician and your Hospice team.

Disposal of medications

Medication that is no longer needed or that has expired should be disposed of safely. Your Cornerstone Hospice Nurse will discuss the safe disposal of medication and destroy Hospice Medication no longer needed in accordance with Cornerstone Policy and Procedure.

Equipment pickup

Someone from the Cornerstone team will make arrangements for the pick-up of any equipment you needed for the care. It is usually picked up within 24 hours but is up to your discretion if you need it out that day or in a few days.
Funeral Planning

Many people have never dealt with funeral planning. The following are frequently asked questions which we hope, along with talking with the funeral director or Hospice social worker or clergy, will help you plan according to your wishes.

WHAT IS FUNERAL PLANNING? It’s making decisions about a funeral ahead of time. It involves:
- Choosing the ceremony that meets your wishes.
- Dealing with emotional, legal and financial issues in advance.
- Making wise choices, so you can have the kind of funeral that’s best for you, your family and loved ones.
- Choosing how to be buried.

WHY THINK ABOUT FUNERAL PLANNING NOW? A funeral is an important event. Once arrangements are made, the worry can be put out of your mind and you can concentrate on enjoying quality time to the fullest.
- It enables family and friends to come together to express feelings of caring, grief, and sadness.
- It helps family and friends accept the reality of death, so they can overcome the emotional pain and work through the adjustment and healing.
- It helps give meaning to a person’s life.
- Funeral planning helps ease the pain. By planning now, you can relieve stress and take away some of the burden on family and friends later.

WHY DOES THE FUNERAL DIRECTOR PLAY AN IMPORTANT ROLE? The funeral director can help plan the funeral and the ceremony, if any, as well as offer advice on
- Funeral service options.
- Caskets and other merchandise.
- Preparation and care of the body.
- Memorial stone or cemetery marker.
- Arranging important details such as contacting clergy, pallbearers, selecting music, arranging transportation for the body and family members before and after the funeral, and making arrangements for burial in another state.

The funeral director can also help handle paperwork including death certificates, obituaries and claims for survivor’s benefits, insurance, social security, or burial at a National Cemetery, if a veteran.

HOW DO YOU PAY FOR A FUNERAL? Cost is an important factor in planning a funeral. These sources of income may be available.
- Social Security (a limited amount).
- The Veterans Administration (VA) if in a National Cemetery.
- Prepayment Plans—You pay for the funeral in advance through a lump sum or installment payments. Investigate the plan carefully before choosing.
- Life Insurance—If you have a life insurance policy, you can use it to assign payment of funeral expenses later.
- A Savings Account or Trust—Once you’ve determined how much you want to pay for the funeral, you can set up a special savings account or trust to meet the expenses.
- Other sources—Benefits may be available from a union or employer pension fund or from certain fraternal groups or professional organizations or community service funds.

Ask your funeral director for details. Talk with your attorney or other financial advisor before you make a decision or enter into any agreements.

Your Cornerstone Hospice Social Worker or Chaplain can also assist you with these details.
Anticipatory Grief

Everyone is familiar with the term “grief”, and it is usually thought of as an emotion that follows a significant loss or unwanted change in our lives. This emotion can also be related to the expectation of a significant loss. This is called anticipatory grief.

When faced with a terminal illness, both the patient and loved ones must cope with the reality of the loss of the future they had envisioned for themselves. The emotion associated with this realization is often every bit as powerful and devastating as the eventual loss itself. It is not uncommon to experience feelings of fear, dread, despair, profound sorrow, guilt or even anger. One may also suffer mood swings, insomnia, fatigue, loss of appetite, inability to focus or emotional withdrawal.

During this time, it can be beneficial for both patient and loved ones to communicate their feelings to one another. Patients often feel the need to “put their affairs in order” or to make changes that will ensure the well-being of their loved ones after their death. Loved ones often feel the need to tell the patient how much they love him or her, and how important the patient has been in their lives.

Unfortunately, these things often go unsaid because neither patient nor loved one wants to upset the other.

Your Cornerstone Hospice social worker is trained to assist you in having these types of conversations within, and between, family members and loved ones, and to be a support during this normal period of anticipatory grief. Your chaplain is also available to provide spiritual support in whatever manner reflects your particular belief system. Please reach out to your team and make your needs known. We will walk beside you every step of the way.
Bereavement

While grief is the emotion associated with a painful loss, bereavement is the period of time after a loss during which grief is experienced. The length of the bereavement period is impacted by the closeness of the relationship with the person who died, as well as the length of time spent in anticipation of the death.

Although it is painful, excruciatingly so at times, bereavement is necessary. It is a process that allows adjustment to loss over time. There is no right or wrong way to experience bereavement. While grieving, it is not unusual to have feelings of tension or irritability, mental confusion, or indecisiveness. Forgetfulness is common, as are frequent mood changes and tearfulness. Feelings of guilt or anger are also not unusual. Sleep and appetite patterns may change dramatically. All of these things, and many others, are normal responses to a traumatic situation.

It is natural to want to pursue distractions or to withdraw from others to try to avoid the pain of grief, but this only stalls the process of adjustment in a very distressing place. For many, it is very difficult to reach out and share our innermost feelings, but this is a time when talking with trusted friends or loved ones can make a significant difference in the ability to cope. Often, people are silent in their pain because they believe that they are protecting others from worry or distress. However, this kind of attempt to protect others usually results in more worry and distress for all involved. Once emotional lines of communication are open, it is likely that everyone involved will feel an enormous amount of relief.

It takes strength to allow others to help in times when we feel most vulnerable. Whether it be revealing our fears and emotional pain in conversation, accepting the offer of a meal from a neighbor, or calling us here at Cornerstone Hospice and making an appointment with one of our bereavement counselors, accepting help can be very curative. Please do not hesitate to reach out to us, or to friends and loved ones, during this most difficult time.

“Grief never ends… but it changes. It’s a passage, not a place to stay. Grief is not a sign of weakness, nor a lack of faith… it is the price of life.”

—Author Unknown
Addendum A- Patient/Family Informed Consent/Advance Directive Information
Release of Information/Rights & Responsibilities

I. CONSENT FOR HOSPICE CARE:
I request admission to Cornerstone Hospice (CH). I acknowledge I have a terminal condition and understand the focus of CH is palliative care providing comfort rather than curative care. I acknowledge a hospice representative has explained the type of care and services that CH may provide during the course of my illness. I acknowledge I was given the opportunity to ask questions regarding the types of care and services I may receive, and I understand the information provided to me by CH. My family, my attending physician (if any), the CH Interdisciplinary team and I will develop my plan of care. I consent to and authorize CH, its physicians, licensed individual practitioners, employees, volunteers and other individuals involved in my care to provide hospice care and services and treatment and perform interventions specified in my plan of care. I have asked family member(s) and significant other(s) to respect the choice of hospice care and to fulfill the role of primary caregiver(s) as able.

II. RELATIONSHIP BETWEEN CH AND PATIENT/FAMILY:
I understand:
• CH promotes the comfort and dignity of patients and addresses the physical, emotional, social and spiritual needs of the patient and family.
• CH services will be provided primarily in my place of residence and/or hospice facility (owned or contracted). If you are currently residing in a facility, hospice staff will coordinate your care with facility staff.
• Patient care is provided by hospice professionals, students and volunteers, both on a scheduled basis and as needed 24 hours a day, seven days a week.
• CH interdisciplinary team does not take the place of my attending healthcare providers, but does CH medical director or physician designee take the place of my attending physician, if one has been identified.
• CH medical director or physician designee provides consultation in pain and symptom management as it relates to my terminal illness as a member of the interdisciplinary team as requested.
• Clinical notes will be made on care records and care plans concerning the medical, nursing, psychosocial, spiritual and personal information required for hospice to fulfill its duties, and give consent and approval for such.
• CH pharmacy may select a medication that is generically equivalent to the brand prescribed by my physician.
• CH documents containing confidential information about me may be left in my home for continuation of care. I agree that I am responsible for protecting the privacy of such information, and I release CH its agents and employees from any and all legal liabilities that may arise from discussions made by the patient and/or caregiver(s).

III. ACKNOWLEDGEMENT OF RECEIPT OF THE FOLLOWING DOCUMENTS:
Notice of Privacy Practices Acknowledgement: I understand that CH's “Notice of Privacy Practices,” as required by federal law provides detailed information about how CH may use and disclose my protected health information (PHI), and also describes my rights concerning my PHI. I understand that I have a right to receive a copy of the Notice of Privacy Practices or that I may review an electronic copy at CH's website, www.cornerstonehospice.org. I acknowledge that I have been offered a paper copy of CH's Notice of Privacy Practices.
Rights & Responsibilities Acknowledgement: I understand that CH's "Patient Rights and Responsibilities" brochure contains important information about my rights and responsibilities as a patient at CH, including a description of CH's procedures for resolution of any complaints.

_________ (Initial) By initiaing I acknowledge that I have received a copy of CH's "Patient Rights and Responsibilities." Notice of Advance Directives: I understand that CH's "Advance Directive Information" brochure has been provided to use and contains important information about advance directives in the State of Florida.

IV. AUTHORIZATION TO RELEASE PRIVATE HEALTH INFORMATION (PHI):
Release of Information: I acknowledge that it is the policy of CH that patient health information is confidential and shall not be disclosed unless permitted or required by law or I have specifically authorized the disclosure in writing. I authorize CH to release my health information: (i) to physicians and other health care practitioners on the CH staff who are involved in my health care now and in the future; (ii) to other health care providers, entities and institutions for the purpose of my continued care and treatment, including referrals, and (iii) to my personal representative. I also authorize CH to release my patient health information to my insurance company, HMO, or other third-party payors, private or governmental, including, but not limited to, the Social Security Administration and its contractors, Medicare, and Medicaid, as necessary to bill and receive payment for my care.
I understand that this authorization extends to all or any part of the records designated above, which may include psychiatric information, genetic counseling/testing, alcohol/drug abuse, AIDS (Acquired Immunodeficiency Syndrome), the result of an HIV test or the fact that an HIV test was performed or sexually transmitted disease. I expressly consent to the release of information as designated above unless initialed below or otherwise required by law.
May NOT include information related to (please initialed):
HIV/AIDS  ____ Mental Health/Psychiatric ______ Drug and/or Alcohol Abuse ______
Genetic Counseling/Testing Information __________ Sexually Transmitted Disease ______

_________ Initial Page 1 of 3

PATIENT AGREEMENT AND
INFORMED CONSENT TO CARE

Patient Name: ____________________________
Medical Record #: ________________________
Team: _________________________________

(Form #3004 Rev 6/13)
V. ELECTION OF HOSPICE MEDICARE/TRICARE:
I elect the Medicare/Ticare Hospice Benefit provided by CH, and I acknowledge, consent and agree to the following:

- The patient, family, attending physician and the CH interdisciplinary team collaborate together to develop an individualized plan of care for the patient/family and determine the appropriate level(s) of care needed.
- I will work with CH and my attending physician to make necessary arrangements for care related to my terminal diagnosis(s) for which CH is treating me. CH will pay for care related to my terminal diagnosis(s), as deemed reasonable and medically necessary.
- The approximate cost and methods of reimbursement through Medicare/Ticare for hospice care has been explained to me. I understand Medicare/Ticare will be billed directly for the cost of my hospice care whether provided within the home, hospital, assisted living facility, nursing home or hospice facility (owned or contracted).
- For the duration of my election to receive Hospice care, I waive all rights to Medicare/Ticare payments: (i) for hospice care other than the care provided by CH, unless such care is provided under an arrangement made by CH and (ii) any Medicare/Ticare services that are related to the treatment of my terminal condition(s) for which hospice was elected, or a related condition, except for services provided by CH or another hospice under an arrangement with CH, or my attending physician. My attending physician is not an employee of CH or does not receive compensation from CH for such services. The care provided by my attending physician who is not employed or under arrangement with CH can be billed to Medicare part B.
- Nursing home and board and care is NOT a hospice Medicare/Ticare approved benefit, other than respite care.
- Should I secure care considering curative outside of the hospice plan of care and without the involvement of CH, I understand I may be financially responsible.
- I understand I may revoke this hospice benefit election, in writing, and be discharged from CH at any time with my original Medicare/Ticare benefits fully restored.
- Care for all illnesses other than my primary terminal diagnosis(s) for which hospice is treating me can be billed to Medicare/Ticare in the traditional manner.

VI. ELECTION OF HOSPICE MEDICAID: (Separate form required.)

I elect the Medicaid Hospice Benefit provided by CH, and I acknowledge, consent and agree to the following:

- The patient, family, attending physician and the CH interdisciplinary team collaborate together to develop an individualized plan of care for the patient/family and determine the appropriate level(s) of care needed.
- I will work with CH and my attending physician to make necessary arrangements for care related to my terminal diagnosis(s) for which CH is treating me. CH will pay for care related to my terminal diagnosis(s), as deemed reasonable and medically necessary.
- The approximate cost and methods of reimbursement through Medicaid for hospice care has been explained to me. I understand Medicaid will be billed directly for the cost of my hospice care whether provided within the home, hospital, assisted living facility, nursing home or hospice facility (owned or contracted).
- For the duration of my election to receive Hospice care, I waive all rights to Medicaid payments: (i) for hospice care other than the care provided by CH, unless such care is provided under an arrangement made by CH and (ii) any Medicaid services that are related to the treatment of my terminal condition(s) for which hospice was elected, or a related condition, except for services provided by CH or another hospice under an arrangement with CH, or my attending physician. My attending physician is not an employee of CH or does not receive compensation from CH for such services. The care provided by my attending physician who is not employed or under arrangement with CH can be billed to Medicaid.
- Should I secure care considered curative outside of the hospice plan of care and without the involvement of CH, I understand I may be financially responsible.
- I understand I may revoke this hospice benefit election, in writing, and be discharged from CH at any time with my original Medicaid benefits fully restored.
- Care for all illnesses other than my primary terminal diagnosis(s) for which hospice is treating me can be billed to Medicaid in the traditional manner.

VII. ELECTION OF INSURANCE HOSPICE BENEFIT:

I elect insurance benefits for hospice care provided by CH, and I acknowledge, consent and agree to the following:

- The approximate cost and methods of reimbursement through insurance for hospice care has been explained to me.
- I understand the decision of CH to accept me into care will not be based upon my ability or inability to pay and the CH services will not be adjusted based on any change in my ability to pay.
- I authorize payment of benefits from any third-party payer directly to CH for services rendered. CH will bill any third-party payer as a courtesy to me.
- I understand I am responsible for all deductibles, co-payments and any cost of services over my insurance benefit limits, based on my ability to pay.
- Is your insurance coverage provided through COBRA? Yes No

<table>
<thead>
<tr>
<th>Insurance Policy #</th>
<th>Group #</th>
</tr>
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<tbody>
<tr>
<td>Insurance Co. Name</td>
<td>Insured Name</td>
</tr>
<tr>
<td>Relationship to Patient</td>
<td></td>
</tr>
</tbody>
</table>

Initial Page 2 of 3
VIII. BENEFIT ELIGIBILITY/VERIFICATION:
- Have you ever been enrolled in another hospice program? Yes No
- Have you filed or plan to file for Social Security disability or other benefits? Yes If yes, date filed ___/___/___ No

IX. OTHER COVERAGE - REQUEST FOR FINANCIAL ASSISTANCE (REA):
I understand any fee for services will be based on my ability to pay. The amount I will be billed for services by CH will be determined by a request for financial assistance. I will be notified in writing within 10 days of any inability amount. If my financial circumstances change or if any bill becomes a hardship for me or my family, I agree to notify CH, if I have questions.

X. MEDICARE/TRICARE SECONDARY PAYOR (MSP):

  MEDICARE =
  Is patient or his/her spouse actively employed? Yes No
  If not employed, retirement date? ___/___/___
  Are services related to an automobile or other accident, including a work-related accident or illness? Yes No
  Is patient entitled to Veterans Administration or Black Lung benefits? Yes No
  Is patient entitled to Medicare/Tricare solely as a result of end-stage renal disease? Yes, Date began ___/___/___ No

  Patient choice: Hospice Medicare/Tricare Hospice Medicaid Private Insurance
                  Private Pay (REA)

Assignment of Benefits: I authorize payment directly to CH of any insurance or other third party benefits (otherwise payable to me) to which I am entitled for my treatment at CH. I understand that I am responsible for providing CH with information necessary to allow CH to bill my insurance. I understand I am financially responsible for payment of any charges not paid by insurance or other third party including if I have no insurance or coverage is denied. I further understand CH does not accept responsibility for collecting my insurance claim or negotiating a settlement on a disputed claim, and that I am responsible for the timely payment of my account(s).

(Print Physician/ARNP full name)
This is the Physician/ARNP who has the most significant role in the determination and delivery of my medical care.

I have read the information on this form (or have had it read to me). I have had an opportunity to ask questions and have had them answered to my satisfaction. I understand and agree to all of the terms above unless otherwise noted. I certify that I am the patient or the patient's legal representative with authority to sign this document on the patient's behalf.

Patient or Authorized Representative Signature: ________________________________

Patient unable to sign because:

Authorized Representative: ________________________________ Date: ___/___/___

(Print name) Representative is acting on patient's behalf as: ☐ Parent (of minor) ☐ Guardian ☐ HCS ☐ DPOA-HC ☐ HC Proxy

Hospice Representative Signature: ________________________________ Date: ___/___/___

Initial Page 3 of 3

PATIENT AGREEMENT AND INFORMED CONSENT TO CARE

Cornerstone
HOSPICE & PALLIATIVE CARE Serving since 1994

Patient Name:
Medical Record #:
Team:

(Format 2019 Dec. 6/11)
Addendum B

PRIVACY

Effective Date: April 14, 2003
Revised: June 26, 2013

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

Who will follow this notice

This notice describes Cornerstone Hospice & Palliative Care, Inc., ("Hospice") practices and that of (a) any health care professional authorized to enter information into your medical record, (b) volunteers we allow to help you while you are receiving Hospice care, (c) all Hospice employees and staff, and (d) physician staff providing care under arrangement with Hospice.

In addition, we have many doctors and other providers giving care to our patients in other locations with whom we contract such as hospitals, skilled nursing facilities and assisted living facilities. For convenience of our patients, we are giving one Notice of Privacy Practices to each patient, instead of notices from multiple physicians and other caregivers. This Notice serves as the notice required under Federal law to be given to patients by Hospice, all members of our Hospice medical staff and all other health care professionals who treat you at any of our locations.

The health care providers covered by this "organized health care arrangement" ("OHCA") will share protected health information with each other, as necessary to carry out your treatment, payment for treatment, and health care operations relating to the OHCA. This arrangement does not mean that the persons participating in the OHCA are involved in a joint business arrangement, or that they are responsible for the acts of one another.

Use/disclosure of health information

Hospice may use your health information for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. Unless otherwise indicated, your health information may be used or disclosed only after Hospice has obtained your written consent or authorization. Hospice has established a policy to guard against unnecessary disclosure of your health information.

The following is a summary of the circumstances under which and purposes for which your health information may be used and disclosed:

TO PROVIDE TREATMENT Hospice may use your health information to coordinate care within Hospice and with others involved in your care, such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist Hospice in coordinating your care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. With your consent, the Hospice also may disclose your health care information to individuals outside of Hospice involved in your care including family members, clergy whom you have designated, pharmacists, suppliers of medical equipment or other health care professionals that Hospice uses in order to coordinate your care.

TO OBTAIN PAYMENT With your consent, Hospice may include your health information in invoices to collect payment from third parties for the care you may receive from Hospice. For example, Hospice may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or Hospice. Hospice also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for Hospice care and the services that will be provided to you.

TO CONDUCT HEALTH CARE OPERATIONS Hospice may use and disclose health care information for its own operations in order to facilitate the function of Hospice and as necessary to provide quality care to all of Hospice’s patients. Health care operations include such activities as: (a) Quality assessment and improvement activities; (b) Protocol development, case management and care coordination; (c) Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment; (d) Professional review and performance evaluation; (e) Training programs including those in which students, trainees or practitioners in health care learn under supervision; (f) Accreditation, certification, licensing or credentialing activities; (g) Auditing, including compliance reviews, medical reviews, legal services and compliance programs; and (h) Business management and general administrative activities of the Hospice.

For example, Hospice may use your health information to evaluate its staff performance, combine your health information with other Hospice patients in evaluating how to more effectively serve all Hospice patients, disclose
your health information to Hospice staff and contracted personnel for training purposes.

**HOSPICE DIRECTORY** Hospice may disclose certain information about you including your name, your general health status, your religious affiliation and where you are in the Hospice facility in a Hospice directory while you are in the Hospice inpatient facility. Hospice may disclose this information to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.

**APPOINTMENT REMINDERS** We may use and disclose health information to contact you with a reminder regarding a visit to you.

**TREATMENT ALTERNATIVES** We may use and disclose health information to tell you about or recommend possible treatment options or alternatives.

**FOR FUNDRAISING ACTIVITIES** Hospice may use information about you including your name, address, phone number, and the dates you received care at Hospice in order to contact you or your family to raise money for Hospice. Hospice may also release this information to an affiliated Hospice foundation. If you do not want Hospice or its affiliates to contact you for our fundraising and you wish to opt out of these contacts, you must call or email our Privacy Officer at 1.888.728.6234.

Federal privacy rules allow hospice to use or disclose your health information without your consent or authorization for a number of reasons including the following:

**WHEN LEGALLY REQUIRED** Hospice will disclose your health information when it is required to do so by Federal, State or local law.

**WHEN THERE ARE RISKS TO PUBLIC HEALTH** Hospice may disclose your health information for public activities and purposes in order to: (a) Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death, and the conduct of public health surveillance, investigations and interventions; (b) To report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration; (c) To notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease; or (d) To an employer about an individual who is a member of the workforce as legally required.

**TO REPORT ABUSE, NEGLECT OR DOMESTIC VIOLENCE** Hospice is allowed to notify government authorities if Hospice believes a patient is the victim of abuse, neglect or domestic violence. Hospice will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

**TO CONDUCT HEALTH OVERSIGHT ACTIVITIES** Hospice may disclose your health information to a health oversight agency for activities including audits, civil, administrative or criminal investigations, inspections, licensure or disciplinary action. Hospice, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

**IN CONNECTION WITH JUDICIAL AND ADMINISTRATIVE PROCEEDINGS** Hospice may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process.

**FOR LAW ENFORCEMENT PURPOSES** Hospice may disclose your health information to a law enforcement official for law enforcement purposes (a) As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process; (b) For the purpose of identifying or locating a suspect, fugitive, material witness or missing person; (c) Under certain limited circumstances, when you are the victim of a crime; (d) To a law enforcement official if Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at Hospice; or (e) In an emergency in order to report a crime.

**TO CORONERS AND MEDICAL EXAMINERS** Hospice may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

**TO FUNERAL DIRECTORS** Hospice may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out
their duties, Hospice may disclose your health information prior to and in reasonable anticipation, of your death.

FOR ORGAN, EYE OR TISSUE DONATION Hospice may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissues for the purpose of facilitating the donation and transplantation.

FOR RESEARCH PURPOSES Hospice may, under very select circumstances, use your health information for research. Before Hospice discloses any of your health information for such research purposes, the project will be subject to an extensive approval process. Hospice will ask your permission if any researcher will be granted access to your individually identifiable health information.

IN THE EVENT OF A SERIOUS THREAT TO HEALTH OR SAFETY Hospice may, consistent with applicable law and ethical standards of conduct, disclose your health information if Hospice, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

MILITARY AND VETERANS If you are a member of the Armed Forces, Hospice may release health information about you as required by military command authorities. Hospice may also release health information about foreign military personnel to the appropriate foreign military authority.

NATIONAL SECURITY AND INTELLIGENCE ACTIVITIES Hospice may release health information about you to authorized federal officials for intelligence, counterintelligence, and other national security activities authorized by law.

PROTECTIVE SERVICES FOR THE PRESIDENT AND OTHERS Hospice may disclose health information about you to authorized federal officials so they may provide protection to the President, other authorized persons or foreign heads of state or conduct special investigations.

INMATES If you are an inmate of a correctional institution or under the custody of a law enforcement official, Hospice may release health information about you to the correctional institution or law enforcement official. This release would be necessary (1) for the correctional institution to provide you with health care; (2) to protect your health and safety or the health and safety of others; or (3) for the safety and security of the correctional institution.

FOR WORKER’S COMPENSATION The Hospice may release your health information for worker’s compensation or similar programs providing benefits for work related injuries or illnesses.

AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION Most uses and disclosures of psychotherapy notes, uses and disclosures of health information for marketing purposes and disclosures that constitute the sale of health information require your written authorization. Other uses and disclosures of your health information that are not described above will be made only with your written authorization. If you or your representative authorizes Hospice to use or disclose your health information, you may revoke that authorization in writing at any time. If you revoke your permission, Hospice will no longer use or disclose health information about you for the reasons covered by your written authorization. You understand that Hospice is unable to take back any disclosures that have already been made with your authorization, and that Hospice is required by law to retain our records of the care provided to you.

Your rights with respect to your health information
You have the following rights regarding your health information that Hospice maintains:

RIGHT TO REQUEST RESTRICTIONS You have the right to request a restriction or limitation on the health information Hospice uses or discloses about you for treatment, payment or health care operations, and to request a limit on the health information Hospice discloses about you to someone who is involved in your care or payment, such as a family member or friend. We are not required to agree to the requested restriction except in the limited situation in which you or someone on your behalf pays for an item or service, and you request that information concerning such item or service not be disclosed to a health insurer. If Hospice does agree, however, Hospice will comply with your request unless the information is needed to provide you with emergency or other vital treatment. To request restrictions, you must tell Hospice (1) what information you want to limit (2) whether you want to limit our use, disclosure, or both; and (3) to whom you want
the limits to apply, for example, disclosure to your spouse. To request restrictions, you must submit your request in writing to our Privacy Officer at the address shown below.

**RIGHT TO RECEIVE CONFIDENTIAL COMMUNICATIONS**
You have the right to request, in writing, that Hospice communicate with you in a certain way. For example, you may ask that Hospice only conduct communications pertaining to your health information with you privately with no other family members present. Hospice will not require that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

**RIGHT TO INSPECT AND COPY YOUR HEALTH INFORMATION**
You have the right to inspect and copy health information about you. Usually, this includes medical and billing records, but does not include psychotherapy notes or information compiled in reasonable anticipation of, or for use in a civil, criminal or administrative action or proceeding. To inspect and copy health information, you must submit your request in writing. If you request a copy of your health information, Hospice may charge a reasonable fee for copying and assembling costs associated with your request.

**RIGHT TO AMEND HEALTH CARE INFORMATION**
If you believe the health information we have about you is incorrect or incomplete, you may ask us to amend the information. That request may be made as long as the information is kept by or for Hospice. A request for an amendment of records must be made in writing. We may deny the request if your request for an amendment is not in writing or does not include a reason to support the request. In addition, we may deny your request if you ask us to amend information that: (a) was not created by us, unless the person or entity that created the information is no longer available to make the amendment; (b) is not part of the health information kept by or for Hospice; (c) is not part of the information which you would be permitted to inspect and copy; or (d) is accurate and complete.

**RIGHT TO AN ACCOUNTING**
You have the right to request an accounting (list) of certain types of disclosures we have made of your health information. We are not required to account for certain disclosures such as: (a) disclosures you authorize; (b) disclosures to carry out treatment, payment and healthcare operations; and (c) disclosures to persons involved in your care. The request for an accounting must be made in writing to our Privacy Officer. Your request must state a time period, which may not be longer than six years, and may not include dates before April 14, 2003. The first list you request within a 12-month period will be free. There may be a charge for additional requests. We will notify you of the cost involved and you may choose to withdraw or modify your request at that time before any costs are incurred.

**RIGHT TO BE NOTIFIED OF A BREACH**
You have the right to be notified in the event that we (or one of our Business Associates) discover a breach of unsecured protected health information involving your medical information.

**RIGHT TO A PAPER COPY OF THIS NOTICE**
You have a right to a paper copy of this notice anytime. You may also obtain a copy of the current version of Hospice’s Notice of Privacy Practices on our website.

**Duties of the Hospice**
Hospice is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. Hospice is required to abide by terms of this Notice as may be amended from time to time. Hospice reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If Hospice changes its Notice, Hospice will post a revised copy of the current notice at each of the Hospice facilities and on its website reflecting its effective date.

**Complaints**
If you believe your privacy rights have been violated, you may file a complaint with Hospice or with the Secretary of the U.S. Department of Health and Human Services. To file a complaint with Hospice contact the Privacy Officer designated below. All complaints must be submitted in writing. You will not be penalized for filing a complaint.

**Contact person**
Privacy Officer or Designee
Cornerstone Hospice & Palliative Care, Inc.
2445 Lane Park Road
Tavares, FL 32778
1.888.728.6234
Addendum C

INFORMATION FOR HOSPICE PATIENTS—Registered With Special Needs

The following information should be supplied by the hospice to those patients registered with the special needs registry, so they will be prepared prior to an evacuation to a special needs shelter.

Needs Registry

Please note: The special needs shelter is intended to be a place of last refuge. The evacuee may not receive the same level of skilled care received from staff in the home, and the conditions in a shelter might be stressful.

1. It is recommended that if the special needs registrant has a caregiver, the caregiver shall accompany the special needs registrant and remain with the registrant at the special needs shelter.

2. The following is a recommended list of what special needs registrants need to bring with them to the special needs shelter during an evacuation:
   - Bed sheets, blankets, pillow, folding lawn chair, air mattress
   - The special needs registrant’s medication, supplies and equipment list supplied by the hospice, including the phone, beeper and emergency numbers for the special needs registrant’s physician, pharmacy and, if applicable, oxygen supplier; supplies and medical equipment for the special needs registrant’s care; advance directive including the Do Not Resuscitate (FNR0) form, if applicable
   - Name and phone number of the special needs registrant’s hospice
   - Prescription and non-prescription medication needed for at least 72 hours; oxygen for 72 hours, if needed
   - A copy of the special needs registrant’s plan of care
   - Identification & current address
   - Special diet items, non-perishable food for 72 hours & 1 gallon of water per person per day
   - Glasses, hearing aids and batteries, prosthetics and any other assistive devices
   - Personal hygiene items for 72 hours
   - Extra clothing for 72 hours
   - Flashlight and batteries
   - Self-entertainment and recreational items, i.e., books, magazines, quiet games

3. Special needs registrants need to know the following:
   - It is recommended that if the registrant has a caregiver, the caregiver accompany the special needs registrant. A special needs shelter can accommodate one caregiver at a time, and other family members, friends, etc. should go to a general population shelter.
   - The special needs registrant’s caregiver will have floor space provided. The caregiver must provide his or her own bedding.
   - Check with the local emergency management agency regarding service dogs in the shelter. However, check with your local Emergency Management office to see if other pets are permitted.
   - Bring personal snacks, drinks, and any special dietary foods for 72 hours. It is possible only sparse meals will be provided.
   - Caregivers who regularly assist the special needs registrant in the home are expected to continue to do the same care in the shelter.

†Caregivers can be relatives, household members, guardians, friends, neighbors and volunteers.

DOEA Form H-001, March 2007
Rule 58A-2.026, F.A.C.

Addendum D

HEALTH CARE ADVANCE DIRECTIVES—The Patient’s Right to Decide

Every competent adult has the right to make decisions concerning his or her own health, including the right to choose or refuse medical treatment.

When a person becomes unable to make decisions due to a physical or mental change, such as being in a coma or developing dementia (like Alzheimer’s disease), they are considered incapacitated. To make sure that an incapacitated person’s decisions about health care will still be respected, the Florida legislature enacted legislation pertaining to health care advance directives (Chapter 765, Florida Statutes). The law recognizes the right of a competent adult to make an advance directive instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures; to designate another individual to make treatment decisions if the person becomes unable to make his or her own decisions; and/or to indicate the desire to make an anatomical donation after death.
By law hospitals, nursing homes, home health agencies, hospices, and health maintenance organizations (HMOs) are required to provide their patients with written information, such as this pamphlet, concerning health care advance directives. The state rules that require this include 58A-2.0232, 59A-3.254, 59A-4.106, 59A-8.0245, and 59A-12.013, Florida Administrative Code.

Questions about health care advance directives

WHAT IS AN ADVANCE DIRECTIVE? It is a written or oral statement about how you want medical decisions made should you not be able to make them yourself and/or it can express your wish to make an anatomical donation after death. Some people make advance directives when they are diagnosed with a life-threatening illness. Others put their wishes into writing while they are healthy, often as part of their estate planning.

Three types of advance directives are

• A Living Will
• A Health Care Surrogate Designation
• An Anatomical Donation

You might choose to complete one, two, or all three of these forms. This pamphlet provides information to help you decide what will best serve your needs.

WHAT IS A LIVING WILL? It is a written or oral statement of the kind of medical care you want or do not want if you become unable to make your own decisions. It is called a living will because it takes effect while you are still living. You may wish to speak to your health care provider or attorney to be certain you have completed the living will in a way that your wishes will be understood.

WHAT IS A HEALTH CARE SURROGATE DESIGNATION? It is a document naming another person as your representative to make medical decisions for you if you are unable to make them yourself. You can include instructions about any treatment you want or do not want, similar to a living will. You can also designate an alternate surrogate.

WHICH IS BEST? Depending on your individual needs you may wish to complete any one or a combination of the three types of advance directives.

WHAT IS AN ANATOMICAL DONATION? It is a document that indicates your wish to donate, at death, all or part of your body. This can be an organ and tissue donation to persons in need, or donation of your body for training of health care workers. You can indicate your choice to be an organ donor by designating it on your driver’s license or state identification card (at your nearest driver’s license office), signing a uniform donor form (seen elsewhere in this pamphlet), or expressing your wish in a living will.

AM I REQUIRED TO HAVE AN ADVANCE DIRECTIVE UNDER FLORIDA LAW? No, there is no legal requirement to complete an advance directive. However, if you have not made an advance directive, decisions about your health care or an anatomical donation may be made for you by a court-appointed guardian, your wife or husband, your adult child, your parent, your adult sibling, an adult relative, or a close friend. The person making decisions for you may or may not be aware of your wishes. When you make an advance directive, and discuss it with the significant people in your life, it will better assure that your wishes will be carried out the way you want.

MUST AN ATTORNEY PREPARE THE ADVANCE DIRECTIVE? No, the procedures are simple and do not require an attorney, though you may choose to consult one. However, an advance directive, whether it is a written document or an oral statement, needs to be witnessed by two individuals. At least one of the witnesses cannot be a spouse or a blood relative.

WHERE CAN I FIND ADVANCE DIRECTIVE FORMS? Florida law provides a sample of each of the following forms: a living will, a health care surrogate, and an anatomical donation. Elsewhere in this pamphlet we have included sample forms as well as resources where you can find more information and other types of advance directive forms.

CAN I CHANGE MY MIND AFTER I WRITE AN ADVANCE DIRECTIVE? Yes, you may change or cancel an advance directive at any time. Any changes should be written, signed and dated. However, you can also change an advance directive by oral statement; physical destruction of the advance directive; or by writing a new advance directive. If your driver’s license or state identification card indicates you are an organ donor, but you no longer want this designation, contact the nearest driver’s license office to cancel the donor designation and a new license or card will be issued to you.

WHAT IF I HAVE FILLED OUT AN ADVANCE DIRECTIVE IN ANOTHER STATE AND NEED TREATMENT IN FLORIDA? An advance directive completed in another state, as described in that state’s law, can be honored in Florida.
WHAT SHOULD I DO WITH MY ADVANCE DIRECTIVE IF I CHOOSE TO HAVE ONE? If you designate a health care surrogate and an alternate surrogate be sure to ask them if they agree to take this responsibility, discuss how you would like matters handled, and give them a copy of the document.

• Make sure your health care provider, attorney, and significant persons in your life know you have an advance directive and where it is located. You also may want to give them a copy.
• Set up a file where you can keep a copy of your advance directive (and other important paperwork). Some people keep original papers in a bank safety deposit box. If you do, you may want to keep copies at your house or information concerning the location of your safety deposit box.
• Keep a card or note in your purse or wallet that states that you have an advance directive and where it is located.
• If you change your advance directive, make sure your health care provider, attorney and the significant persons in your life have the latest copy.
• If you have questions about your advance directive you may want to discuss these with your health care provider, attorney, or the significant persons in your life.

For more information
Before making a decision about advance directives you might consider additional options and other sources of information, including the following:

• As an alternative to a health care surrogate, or in addition to, you might want to designate a durable power of attorney. Through a written document you can name another person to act on your behalf. It is similar to a health care surrogate, but the person can be designated to perform a variety of activities (financial, legal, medical, etc.). You can consult an attorney for further information or read Chapter 709, Florida Statutes.
• If you choose someone as your durable power of attorney be sure to ask the person if he or she will agree to take this responsibility, discuss how you would like matters handled, and give the person a copy of the document.
• If you are terminally ill (or if you have a loved one who is in a persistent vegetative state) you may want to consider having a pre-hospital Do Not Resuscitate Order (DNRO). A DNRO identifies people who do not wish to be resuscitated from respiratory or cardiac arrest. The pre-hospital DNRO is a specific yellow form available from the Florida Department of Health (DOH). Your attorney, health care provider, or an ambulance service may also have copies available for your use. You, or your legal representative, and your physician sign the DNRO form. More information is available on the DOH website, www.doh.state.fl.us or myflorida.com (type DNRO in these website search engines) or call 850.245.4440.
• When you are admitted to a hospital the pre-hospital DNRO may be used during your hospital stay or the hospital may have its own form and procedure for documenting a Do Not Resuscitate Order.
• If a person chooses to donate, after death, his or her body for medical training and research the donation will be coordinated by the Anatomical Board of the State of Florida. You, or your survivors, must arrange with a local funeral home, and pay, for a preliminary embalming and transportation of the body to the Anatomical Board located in Gainesville, Florida. After being used for medical education or research, the body will ordinarily be cremated. The remains will be returned to the loved ones, if requested at the time of donation, or the Anatomical Board will spread the remains over the Gulf of Mexico. For further information contact the Anatomical Board of the State of Florida at 800.628.2594 or www.med.ufl.edu/anabtd.
• If you would like to learn more on organ and tissue donation, please visit the Joshua Abbott Organ and Tissue Donor Registry at http://www.donatelifeflorida.org/ where you can become organ, tissue and eye donors online. If you have further questions about organ and tissue donation you may want to talk to your health care provider.

Various organizations also make advance directive forms available. One such document is “Five Wishes” that includes a living will and a health care surrogate designation. “Five Wishes” gives you the opportunity to specify if you want tube feeding, assistance with breathing, pain medication, and other details that might bring you comfort such as what kind of music you might like to hear, among other things. You can find out more at

• Aging with Dignity // agingwithdignity.org // 888.594.7437

Other resources include:

• American Association of Retired Persons (AARP) aarp.org (Type “advance directives” in the search engine)
• Your local hospital, nursing home, hospice, home health agency, and your attorney or health care provider may be able to assist you with forms or further information.
• Brochure: End of Life Issues floridahealthfinder.gov // 888.419.3456
FLORIDA MEDICAID HOSPICE CARE SERVICE
Election Statement

• The Florida Medicaid Hospice Care Services program has been explained to me. I have been given the opportunity to discuss the benefits, requirements, and limitations of this program and the terms of the election statement. I understand that I will be entitled to elect Medicaid hospice care coverage as long as I am Medicaid eligible and I am certified by the hospice physician as being terminally ill.

• I understand that by signing the election statement, I am waiving all rights to Medicaid services for the duration of the election of hospice care for the following services:
  1. Hospice care provided by a hospice other than the hospice designated by me (unless provided under arrangements made by the designated hospice); and
  2. Any Medicaid services that are related to the treatment of the condition, or a related condition, for which hospice care was elected or that the equivalent to hospice care with the following exception: services provided by my attending physician (if that physician is not employed by the designated hospice or receiving compensation from the hospice for those services).

• I understand that I may revoke the hospice benefit at any time by signing a statement to that effect, specifying the date when the revocation is to be effective and submitting the statement to the hospice prior to that date. At that time, I understand my rights to other Medicaid services will resume, provided I continue to be Medicaid eligible.

• By signing this statement, I am electing the following hospice to provide me with the services of the Medicaid hospice care program:

________________________________________________________________________________________
Name of Hospice

________________________________________________________________________________________
Signature of Participant or Representative

________________________________________________________________________________________
Signature of Hospice Representative

Help available 24/7 at 888.728.6234 // We're in your corner."
MEDICATION AGREEMENT

I am entering into an Agreement with Cornerstone Hospice regarding the prescription of controlled medications for the purposes of symptom management.

I agree to the following:

• I will report all medications that I am taking, including over the counter and herbal medications, to the hospice nurse/physician. I will report any side effects from the medications that I take.

• I will take all medications as ordered by the physician. If the medication(s) I am taking is not effective, I will report this to the hospice nurse/physician.

• When requested, I will make all medications available to the hospice nurse/physician to be monitored and counted.

• I will not share, sell, or otherwise allow others access my medications. I will take the highest possible degree of care with my medication and prescription and make sure they are not left where others might see or otherwise have access to them. These drugs may be hazardous or lethal to a person who is not tolerant to their effects, especially a child. I will keep them out of reach of such people.

• I understand that early refills will generally not be permitted and my medications will not be replaced if lost, stolen, or otherwise destroyed.

• I agree to allow Cornerstone Hospice to destroy medications no longer needed or that have expired in accordance with their policy & procedure.

I agree that I have read and understand this medication agreement. I agree to adhere to all terms listed in this Agreement. It is understood that failure to adhere to any of these policies may result in cessation of therapy with controlled medications prescribing by Cornerstone Hospice, referral for further specialty treatment, and/or termination from services.

_________________________________________________________________
Signature of Patient or Legal Representative / Relationship to Patient Date
_________________________________________________________________
Signature of Hospice Representative Date

MEDICATIONS AGREEMENT

Patient Name:

Medical Record #:

Team:
Addendum G

MEDICATION DISPOSAL

Policy

Controlled and other prescription medications no longer needed by the patient will be disposed of in compliance with Cornerstone Hospice procedure which will meet the requirements of all local, State, and Federal laws.

NOTE: Do not dispose of medications if the body will be going to the Medical Examiner. Follow Medical Examiner’s instructions and document accordingly.

Procedure for patient home including assisted living facility

1. Patients and/or their caregiver(s) will receive instruction from the hospice nurse/designee regarding appropriate destruction of medication(s).
2. Disposal of prescription medication(s) will be encouraged when the patient no longer requires the medication.
3. Controlled Substances
   a. Controlled substances will be destroyed at patient’s place of residence at the time of the patient’s death, when the patient no longer requires the medication(s), or when the medication is past the expiration date.
   b. Controlled substances must be destroyed by flushing or slurry.
   c. There must be a witness to destruction of controlled substances. In the home setting the following witnesses are acceptable:
      i. Any other individual in the home (caregiver, family member, friend)
      ii. Another hospice staff member
   d. In the event the caregiver refuses to allow disposal of controlled substances, the hospice representative will:
      i. Educate the caregiver that Federal law prohibits use of controlled substances by anyone other than the person they are prescribed for.
      ii. Document the following on the Medication Disposal Record:
         1. The name of the drug
         2. The strength of the drug
         3. The quantity of the drug not destroyed
         4. Education regarding destruction of medication
      iii. The hospice representative may not transport any controlled medications in their personal vehicles.
   e. NOTE: If the home patient has a Comfort, Cardiac, Pediatric and/or Seizure Kit placed in the home and moves out of the service area, withdraws from the program, or transfers to a nursing home or inpatient setting, or the kit is past the 1 year expiration date, the kit must be destroyed.
4. Slurry Method
   a. Medications should be destroyed in either their original container or placed in a disposable container that has a lid. Some examples of disposable containers are plastic beverage bottles, plastic detergent bottles, coffee cans.
   b. Medications should be rendered unusable by adding rubbing alcohol or water to the container with the medication followed by corn starch, flour, baby powder, or kitty litter. (This is commonly called a “slurry method” of destruction.)
   c. The container of unusable medication may be disposed of in the regular trash. Place the container in a plastic bag and dispose of as you would any other trash.
   d. The following methods should be utilized to render medications unusable.
      i. Liquids:
         1. Add corn starch, flour, baby powder, or kitty litter to the container and recap or empty medication into a disposable container, add corn starch, flour, baby powder, or kitty litter to the container and cap.
      ii. I.V. Medications:
         1. Transfer, empty, or drain medication into a disposable container
            a. Empty I.V. medication from the cassette or bag.
            b. Evacuate multi-dose vials via syringe.
            c. Ampules of injectable medication should be snapped open and drained. Dispose of empty ampules in a sharps container.
2. Add corn starch, flour, baby powder, or kitty litter to the container and cap.

iii. Tablets and Capsules:
1. Add rubbing alcohol or water to the container followed by corn starch, flour, baby powder, or kitty litter and recap or empty medication into a disposable container.

iv. Suppositories:
1. Remove suppositories from foil or other outer wrap.
2. Place opened suppositories in a disposable container.
3. Add rubbing alcohol or water to the container.
4. Add corn starch, flour, baby powder, or kitty litter and cap.

v. Transdermal Patches:
1. Use disposable gloves to remove patches from their packaging and remove backing.
2. Place unwrapped patches in a disposable container.
3. Add rubbing alcohol or water to the container.
4. Add corn starch, flour, baby powder, or kitty litter and cap.
5. Do not cut or puncture patches

vi. Medicated Ointments and Creams:
1. Mix corn starch, flour, baby powder, or kitty litter into the original container.
2. Squeeze or scoop medication into a disposable container.
3. Mix corn starch, flour, baby powder, or kitty litter into the container and cap.

vii. In the instance that the above method is not practical, medications may be disposed of by flushing without wrappers.

5. Disposal of all hospice medications will be documented utilizing the Medication Disposal Record Form #3026. The documentation will include:
   a. The name of the drug
   b. The strength of the drug
   c. The quantity destroyed
   d. The method of disposal
   e. The signature and title of the staff member destroying the medication
   f. The signature of the witness
   g. The date

6. In the event the caregiver refuses to allow disposal of hospice supplied medications, the hospice representative will:
   a. Educate the caregiver regarding the dangers of taking medications prescribed for another individual.
   b. Document the following on the Medication Disposal Record:
      i. The name of the drug
      ii. The strength of the drug
      iii. The quantity of the drug not destroyed
      iv. Education regarding destruction of medication
      v. Refusal to destroy medication
      vi. The signature and title of the staff member
      vii. The signature of the individual refusing destruction
      viii. The date.

Procedure for nursing home/ALF or hospital
1. Hospice will follow the medication disposal protocols for each nursing facility.
2. The Hospice nurse/designee should not destroy the medications in nursing homes but could assist the facility staff as a witness.
3. Fill out Medication Disposal Form #3026 and state that the medications were destroyed per facility protocol.
4. A hospice staff visit to the patient’s home to destroy medication should be scheduled with the family/caregiver if hospice medications were left in the home, following the above listed procedures.

Hospice house death or discharge from hospice
1. If the patient is in a Cornerstone Inpatient Facility, the RN/designee will dispose of the patient’s medication in accordance with Policy #HHS-13.
2. If any medications have been left in the patient’s home, the hospice house staff should notify the home team to arrange for a visit to destroy any remaining medications.
Addendum H

COMPLAINT OR GRIEVANCE PROCEDURES

We want to hear from you if you have any complaints or concerns about our staff or the care you are receiving.

Contact our Vice President of Quality and Compliance at 352.343.1341 or toll free at 888.728.6234

Additional contact information

State Hospice Organization:
Florida Hospice & Palliative Care, Inc
1.850.878.2632

To report abuse, neglect, exploitation
Please call toll-free
1.800.962.2873

To get help with your Medicare questions:
Please call toll-free
1.800.MEDICARE
TTY/TDD: 1.877.486.2048

To report complaints, or ask questions about a Medicare certified agency:
Please call toll-free
1.888.419.3456
8:00 AM to 5:00 PM

Addendum I

DEYTA SURVEY FORM

At the end of services, you will receive a Deyta satisfaction survey. Deyta is the National Hospice and Palliative Care Organization’s contractor which manages its Family Evaluation of Hospice Care (FEHC) and measures hospice satisfaction.

Your comments are very important to us. We encourage you to complete the survey to acknowledge Cornerstone Hospice services you received.

Thank you in advance for your assistance.
Lake/Sumter Counties
352.343.1341 Toll Free 888.728.6234

Orange County
407.206.2273 Toll Free 800.679.6088

Osceola County
407.846.1231 Toll Free 800.559.4345

Polk County
863.291.5560 Toll Free 800.503.5756

Hardee/Highlands Counties
863.382.4563 Toll Free 800.503.5756

IN THE EVENT YOU ARE UNABLE TO REACH A CORNERSTONE HOSPICE TEAM MEMBER, CALL

888.728.6234
24 HOURS A DAY
7 DAYS A WEEK

cornerstonehospice.org