

Patient & Family Handbook



HOME HEALTH CARE
PERSONAL CARE
MEMORY CARE
HOSPICE AND PALLIATIVE

Your Hospice Care Team

Nurse _____

Hospice Aide _____

Social Worker _____

Chaplain _____

Volunteer _____

Call us

☐ Daphne 251-626-5255

☐ Dothan 334-794-7847

☐ Marianna 850-482-8520

☐ Mobile 251-478-8671

☐ Ft Walton Beach 850-729-1800

☐ Panama City 850-785-3040

☐ Pensacola 850-202-0840

☐ Tallahassee 850-575-4998

Medication Log



When I get up, I take:

Drug Name (brand name, generic name, dose)	This looks like	How many?	How I take it	I started taking this on:	I stop taking this on:	Why I take it	Who told me to take it



In the afternoon, I take:



In the evening, I take:



Before I go to bed, I take:

Other medications that I do not use every day:

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Welcome to Covenant Care

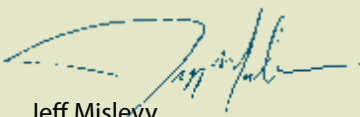
It is truly an honor to serve you and your family at such an uncertain time in your life's journey. We believe you've chosen a care partner that shares your goals: the pursuit of the highest quality of life and an enriching experience for you and your loved ones. For more than 33 years, our name has been our commitment. A "covenant" is a solemn promise, and we promise to provide exceptional, compassionate care as we take this journey with you.

Our primary objective is to ensure comfort and dignity while empowering you with choice. As an Open Access hospice provider, Covenant Care offers a unique approach to end-of-life care, allowing you and your loved ones to benefit from hospice services while continuing to receive many treatments and medications that are not typically offered within a traditional hospice program. This individualized and patient-centered philosophy ensures you remain in control of your care: the right care, at the right time, and in the right place.

From the moment you choose Covenant Care, you become part of our family, so it's only natural that our promise of caring extends beyond the individual to include your loved ones as well. Our interdisciplinary care team will manage a comprehensive care plan that addresses all of your medical, emotional and spiritual needs — and provides support for family members through specialized education and counseling.

Covenant Care believes that every moment is a memory in the making. This is a time for love and reflection. We are humbled you have chosen Covenant Care, and we are privileged to share this experience with you and your family.

You deserve comfort, peace of mind and excellent care. This is our promise.



Jeff Mislavy
President and Chief Executive Officer

How To Contact Us

While all Covenant Care offices are open from 8 a.m. to 5 p.m., Monday through Friday, professional care is available to you **24 hours a day, 7 days a week**. If you need help or have any questions during business hours, please call your local office listed below. Services are also available on an on-call basis after the office is closed. Simply call your local office.

Crestview Area(850) 682-5500
 Delray Beach(561) 538-3430
 Fort Lauderdale Area(954) 694-6383
 Fort Myers(239) 232-4731
 Gainesville.....(352) 681-4449
 Jacksonville.....(904) 456-8476
 Marianna.....(850) 317-8580

On evenings and weekends, call the same numbers for emergency services, including visits and telephone consultation. A member of your Covenant Care Team will be contacted and will call you back as soon as possible.

Orlando Area.....(407) 358-3276
 Panama City(850) 470-9288
 Pensacola(850) 470-9288
 St. Petersburg(727) 800-3261
 Tallahassee.....(850) 403-0480
 Tampa Area.....(813) 530-1238

When should I call on a weekend or after hours?

Below are some of the medical conditions that commonly prompt a call for help on the weekends, holidays and after hours. Please remember these are only examples to aid you in decision-making and are **NOT** to be mistaken for the only reasons to contact on-call staff. Many times, it is better to **call us** so that you and your family member may have peace of mind about your concern.

Covenant Care staff may be able to address your problem by telephone or may decide that a visit is necessary. If you would like a visit to alleviate anxiety or address other concerns, please let us know. If you have questions or notice significant changes or problems, **please call Covenant Care before calling an ambulance, the hospital, "911," or the doctor.** Feel free to call again later if the initial intervention is not effective or if the patient's situation changes.

Please remember to check medications each week on Wednesday and notify your nurse of any refills needed to ensure that you won't run out during the weekend. Please keep this guide in a prominent place near your telephone so that the numbers are readily available to you.

ADVANCE DIRECTIVES FOR HEALTHCARE

Advance Directives are written statements of a person's wishes regarding medical treatment. The directives are prepared to ensure those wishes are known and honored in the event he or she becomes unable to communicate them to a doctor. This section will discuss Living Wills, Healthcare Surrogates, Durable Power of Attorney and Guardianship.

Elder Law in Florida

Planning for your healthcare needs

by John B. Carr, Attorney at Law

When providing care to another, there is a lot to learn about elder law and advance directives. This article outlines some of the basic principles. If you have any questions, we recommend you speak with an elder law attorney who may be able to give you advice specific to your situation.

Before we begin, here are some key definitions to keep in mind:

Terminal Condition means a condition caused by injury, disease or illness from which, within a reasonable degree of medical certainty, there can be no recovery and which reasonably can be expected to cause death; or a persistent vegetative state characterized by a permanent and irreversible condition of unconsciousness in which, within a reasonable degree of medical certainty, there is the absence of voluntary action or cognitive behavior of any kind and an inability to communicate or interact purposefully with the environment.

Life-Prolonging Procedure means any medical procedure, treatment or intervention which uses mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function and, when applied to a patient in a terminal condition, serves only to prolong the process of dying. The decision whether a treatment is life-prolonging depends upon your circumstances and will be made by your attending physician. Hydration and nutrition may be considered life-prolonging procedures if administered through an invasive medical procedure. Comfort medication is never a life-prolonging procedure.

Living will

What is a living will?

The living will is a document you can prepare when you are competent, which sets out your care preferences if you become incapable of making medical decisions and suffer from a **terminal condition**.

In a living will you can:

- Indicate a person to carry out your wishes and state what types of life-prolonging procedures you would want or not want, including the types of circumstances under which you would want these procedures used, withheld or withdrawn.
- Discuss other issues, which may be important to you if you become terminally ill; for example, the role your religious preferences will play in care decisions.

How do you prepare a living will?

You might want to talk to your attorney before you complete a living will.

The living will must:

- Be in writing.
- Be signed by two witnesses (both of whom cannot be a spouse or immediate family member) who know your identity and who know you are aware of what you are signing and competent to sign.
- Address terminal illness and life-prolonging procedures.

Anyone can prepare a living will, but you must be a capable, competent adult in order to sign the living will. Your family cannot sign one for you. You can and should designate someone in your living will to carry out its terms. This person is called a surrogate.

What can a living will do?

Preparing a valid living will and delivering it to your healthcare provider is the best assurance that:

- If you become incapable of giving your informed consent for medical decisions; and two doctors certify that you are in a terminal condition, then your wishes as to life-prolonging measures will be carried out.
- Except under certain circumstances as set out by law, your family cannot override your wishes. Your doctor cannot override your living will and could transfer you to another physician if he feels he cannot comply with your wishes. However, bear in mind that you cannot authorize someone to commit euthanasia or assist you in committing suicide under a living will.

A living will is not effective until it is delivered to your healthcare provider. That responsibility belongs to you. Remember to whom you have delivered copies so that if you amend or revoke your living will, you can recover all copies. Your living will expires upon your death.

What if I decide I don't want a living will?

You may revoke your living will:

- By means of assigned, dated writing;
- By means of the physical cancellation or destruction of the declaration by the or by another in the declarant's presence and at the declarant's direction;
- By means of an oral expression of intent to revoke; or
- By means of subsequently executed living will that materially differs. Any such revocation will be effective when communicated to the attending physician. No civil or criminal liability shall be imposed upon any person for a failure to act upon a revocation unless that person has actual knowledge of such revocation.

What will happen if you don't have a living will?

If you do not have a living will, your healthcare provider can appoint a proxy to make your life-prolonging decisions. Also, if you have appointed a healthcare surrogate, and have not specifically restricted the authority of the surrogate, the healthcare surrogate can make life-prolonging decisions. Remember that this is an important document and should be prepared only with a great deal of forethought on your part. If you have any questions about the contents of a living will or the meaning of its language, you may wish to confer with your family, friends, attorney, healthcare providers, spiritual advisor or others.

Healthcare Surrogate

What is a healthcare surrogate?

Florida law permits you to name a surrogate healthcare decision maker to make your medical decisions if you are not able to give informed consent. While you must name a healthcare surrogate while you are capable of making medical decisions, the healthcare surrogate does not assume responsibilities until such time as you become incapable of making your medical decisions.

How do I designate a surrogate?

Your declaration must be in writing, signed by two witnesses, both of whom cannot be a spouse or immediate family member. Your named surrogate cannot be a witness. Your healthcare surrogate is presumed to make all of your medical decisions, including life-prolonging decisions, except if there is a living will. If you wish the authority of your surrogate to be limited, you must so specifically state in the healthcare surrogate form. Your designation of healthcare surrogate expires upon your death.

When is a surrogate used?

Your declaration only becomes effective when your attending physician determines that you do not have the capacity to make healthcare decisions. You do not need a judge to declare you legally incompetent in order for your healthcare surrogate to make your healthcare decisions. If you become incapable of making medical decisions, a second physician will examine you. The results of the two examinations will be placed in your records.

Upon determination of your inability to make medical decisions, your healthcare surrogate will be notified that he/she should assume responsibility for making your medical decisions. If you regain competency, your healthcare surrogate ceases to act on your behalf.

What can my healthcare surrogate do?

- Review your medical records
- Consult with your healthcare providers
- Give medical consent
- Apply for medical benefits on your behalf

What can't my surrogate do?

- Authorize electroshock therapy
- Authorize sterilization
- Authorize psychosurgery
- Authorize voluntary admission to a mental hospital
- Withhold life-prolonging procedures if you are pregnant

What if I don't have a healthcare surrogate?

In the event you do not name a healthcare surrogate and you are a resident in a healthcare facility, or your healthcare surrogate is not able to act on your behalf, the facility can obtain a person willing and competent to act as your healthcare proxy.

Durable Power of Attorney (DPOA)

What is a durable power of attorney?

Florida Statutes permit a durable power of attorney. It is a document that specifies exactly the powers which you are giving to the person holding the durable power of attorney. This may include, but is not limited to, arrangement for and consent to medical, therapeutic and surgical procedures, including the administration of drugs. Durable powers of attorney can also relate to things such as transfer of property, borrowing money, handling bank accounts, etc.

How do I designate a durable power of attorney?

There is no set form for a durable power of attorney. The document should specify the date that it becomes effective. In order for a durable power of attorney to remain effective should you become fully incompetent, it must include language which states that it is not affected by your disability, except as provided by statute. You may use any words so long as the intent is clear. A Durable Power of Attorney must be notarized and signed by two witnesses (both of which cannot be a spouse or immediate family member).

Who can hold a durable power of attorney?

Under Florida law, you can name any adult you choose to act as your agent under a durable power of attorney. This need not be a family member but should be a person who knows your wishes. If the person is related to you, you must so state in your power of attorney. Once you have prepared a power of attorney, the person holding the power of attorney cannot delegate therapeutic or surgical procedures for the principal, including the administration of drugs; the agent must attempt to carry out the wishes of the person.

Does a durable power of attorney expire?

A durable power of attorney expires at the time of death, at the time you revoke the power, or if you are adjudicated "incompetent" by a court of law unless the Durable Power of Attorney states otherwise.

Guardianship

Florida has very detailed guardianship laws. Filing should be done by an attorney. In order to have a guardianship appointed for a person, the following steps must be taken:

- A petition must be filed with the circuit court to determine your incapacity.
- A petition must be filed to appoint a guardian.
- A budget and care plan must be prepared.
- The guardian must make periodic reporting.

You will have an attorney appointed to represent your interests. You will be examined by a panel of three to determine the scope of your incapacity. The costs associated with the guardianship may be borne by your estate, if you have personal property.

The power of that guardian may encompass all of your decision-making power or may be limited in power, as determined by law. A guardian will be under limited supervision of the court and must explain to the court from time to time how your decisions are being made and how your assets are being handled. Upon appointment of a guardian, the court will determine whether a valid advance directive exists and may specify what authority, if any, the guardian shall have over surrogate, and the court may order revocation of the advance directive.

Elder Law in Alabama

By Amanda C. Hines, Esq.

Durable Power Of Attorney (POA)

A power of attorney that designates an attorney-in-fact in writing that contains the words “this power of attorney shall not be affected by disability, incompetency or incapacity of the principal” or similar words that show it is the principal’s intent that the authority conferred by the POA shall be exercisable despite the principal’s subsequent disability, incompetency or incapacity.

All acts done by agent pursuant to a durable power of attorney during any period of disability, incompetency or incapacity will have the same effects and inure to the benefit of and bind the principal, his successors and assigns so be careful who you trust.

Safeguard: Name more than one person.

Attorney-in-fact has fiduciary duties.

Revocation and Termination of POA

Terminates at death so long as there is actual knowledge of the principal’s death.

May be revoked in writing.

Can be revoked by a court of competent jurisdiction.

Having a durable power of attorney avoids the need for guardianship and conservatorship in most cases.

Living Will and Healthcare Proxy Designations

Any competent adult over the age of 18 may execute a living will directing the providing, withholding, or withdrawal of life sustaining treatment and artificially provided nutrition and hydration.

Any competent adult over the age of 18 may execute a living will that includes a written health care proxy designation appointing another competent adult to make decisions regarding the providing, withholding, or withdrawal of life sustaining treatment and artificially provided nutrition and hydration.

A living will and/or health care proxy designation may be revoked at any time by doing any of the following:

- Destroying document in a manner indicated intent to cancel,
- By written revocation signed and dated by the declarant or
- Verbal expression of intent to revoke made by the declarant to a competent adult over the age of 18 who signs and dates a writing confirming the revocation.

How do I prepare living will and/or health care proxy designations in Alabama

- Must be in writing.
- Must be signed by declarant and include the written acceptance of the named healthcare proxy or proxies (may be by another person in the declarant's presence and by the declarant's express direction.)
- Must have two independent witnesses age 19 and older.
- Declarant is responsible for providing a copy of the advance directive for healthcare to his or her attending physician or other healthcare providers providing services to the declarant.

The advance directive for health care becomes effective when:

- Attending physician determines one can no longer understand, appreciate, or direct medical care; and
- Two physicians, one being the treating physician, determines the following: Terminal illness or permanent unconsciousness.

Guardianship and Conservatorship

Upon the filing of a petition with a court of competent jurisdiction, the court can appoint a guardian and/or conservator over a person who the court determines to be incompetent. This can become very expensive. A guardian is responsible for the health, support, education and/or maintenance of an incapacitated person.

Who may serve as a guardian?

Unless for good reason shown to the court, the court shall appoint a guardian in accordance with the incapacitated person's most recent nomination in a durable power of attorney. Otherwise the following are entitled to a consideration for appointment in the order listed below:

- Spouse
- An adult child
- A parent
- Any relative with whom the incapacitated person has resided for more than 6 months of prior to filing complaint
- A person nominated by the person who is caring for or paying for the care of the incapacitated person

A court of competent jurisdiction can appoint a conservator to be responsible for the estate and affairs of a person it determines to be incompetent to manage his/her own property and/or business affairs.

Who may serve as a conservator and fulfill the conservator's obligations?

The court may appoint an individual or a corporation with general power to serve as trustee over one's estate. The following are entitled to consideration for appointment in the order listed below:

- A conservator, guardian of property or other fiduciary appointed by an appropriate court of another jurisdiction
- An individual or corporation nominated by the protected person who is age 19 or older and of sufficient mental capacity
- The protected person's most recent nomination under a durable power of attorney
- Spouse
- An adult child
- A parent
- Any relative with whom the incapacitated person has resided for more than 6 months of prior to filing complaint
- A person nominated by the person who is caring for or paying for the care of the incapacitated person
- A general guardian or sheriff for the county who must be appointed and act as conservator when no other fit person files a petition for appointment

The appointed conservator must post a bond to be determined by the court and based on the size of the protected person's estate. The appointed conservator must provide an accounting of the estate upon his/her termination or removal and at least once every three years.

A conservator can be personally liable for any obligations or torts arising out of or committed in the course of administering the estate if the conservator is personally at fault. In most cases, a Power of Attorney can avoid the expensive process of Guardianship and Conservatorship.

How can a guardianships and/or conservatorships be terminated?

A court of competent jurisdiction determines the guardian/conservator to be incompetent, or the guardian or conservator resigns or is removed by the court.

Preparing for the Future: Caregiver and Patient Checklist

As the life-limiting illness progresses, the ability of the patient to be able to care for financial matters and make sound decisions may decline. Primary caregivers, in collaboration with the patient if able, should review and complete the following checklist:

Legal Issues – Contact an attorney for advice regarding Durable Power of Attorney, Health Care Surrogate and Living Will. Check local laws if power of attorney was issued in another state.

Finances – Designate a person to assume responsibility for financial matters.

Checking Accounts (bill payments, etc.)

Savings & Other Accounts (money market, etc.)

Real Estate and Property (location of deeds, etc.)

Will – Make sure it is current. Check state laws if transferring from another state.

Living Will – Locate or create to review your loved one's wishes.

Safety Deposit Box – Find the keys to and designate a co-signer for access.

Bills – Make a list of all bills to be paid if the patient remains at home.

- Electric
- Mortgage
- Phone
- Sewer/Water
- Outside care

Online – Make a list of user names and passwords for email, social media, credit cards, online banking, and other accounts.

Insurance Policies – Locate the following:

- House
- Car
- Medical
- Life insurance
- VA
- Disability

Waiver of Premium – Check for clause on insurance policies.

Driving – Collaborate with care team and physician to determine when it is no longer safe for the patient to operate a motor vehicle.

Social Security –

- Check sent to residence or direct deposit
- Designate representative Payee.
- If under 65, apply for Social Security disability.

Security Box or Safe – Locate key or learn combination.

End-of-Life Arrangements –

Be aware of arrangements for cemetery plot, funeral, etc. If none have been made, ask about wishes regarding burial or cremation.

Autopsy Arrangements – Florida Brain Bank.

Medical History – Keep on file, along with medication names and dosages.

ID Bracelet – Purchase for the patient in case of wandering behavior.

Respite Care – Find available resources to give yourself the time you need.

Our care team can assist you with many of these items.

SAFETY GUIDELINES FOR PATIENT & CAREGIVER

Home care can be a safe and gratifying choice for patients with a challenging illness and their caregivers, but it is helpful to give special attention to the environment in which the patient is cared for so that hazardous conditions can be corrected.

Patient safety guidelines:

- In a **medical emergency**, call the **Covenant Care office** in your area — the phone number is listed at the front of this service guide.
- In a **NON-medical emergency**, such as fire, dial 911.
- Be sure you have access to a phone or medical alert service to call for help when needed.
- For **general safety**, make appropriate changes to adapt your environment to your needs. Consider doing the following, if appropriate:
 - Install **grab bars** in frequently-used areas, such as the kitchen and the bathroom near the toilet and shower
 - Install a **toilet extension** seat to raise the seat
 - Build ramps, install new railings, and repair or replace steps that are difficult to navigate. Block access to **hot spots**, such as stoves and hot water pipes (lower hot water heater temperature to 120° F to avoid burns)
 - Clear walking areas, secure area rugs, repair holes in carpeting, keep stairways well lit, install non-skid treads on stairs, and use night lights
- Limit or avoid **alcohol** use and be aware of side effects of medications (be aware that alcohol interacts with many medications to increase side effects, such as dizziness)
- **Rise slowly** after eating or sleeping to prevent falls related to low blood pressure
- Keep nighttime thermostat set above 65° F to help maintain body temperature
- Practice good personal hygiene, such as **hand washing**, which is the first and best defense against infection
- Read the “Infection Control” section for more detailed information on this subject

Caregiver safety guidelines:

- Discuss with the patient’s physician or nurse how **alcohol**, allergy or other **over-the-counter drugs**, and **vitamins or herbal products** might work against medications for the patient’s illness
- Make sure patient stores and takes all **medications as directed** (consider setting up a daily log to keep track of when he or she takes what medications)
- Take advantage of **home care equipment** that will make the patient’s care safer and easier (this includes canes, walkers, hospital beds, over-the-bed tables, and bedside commodes)
- Side rails have recently been found to pose safety risks for the patient, so discuss the decision to use them with the patient’s nurse. Side rails present the most danger for patients with **memory problems, incontinence, pain, or uncontrolled body movement**; always keep the bed in low position, except during direct patient care (wheels should be locked at all times)
- If the patient is at risk for **falling out of bed**, place mats on the floor next to the bed (think about why the patient might want to get out of bed, and **offer assistance** periodically for such needs as toileting, thirst, hunger, restlessness, and pain)
- Closely **monitor patients who are confused, in pain, incontinent, or have poor physical control**; use the proper size mattress, and reduce gaps between the mattress and the side rails
- Place a **bedside commode** near the bed, if this would be easier for the patient
- Help prevent **pressure sores** by turning the patient frequently, using pressure-reducing pads and mattresses, and stimulating the skin by the use of lotions, moisturizers, and massage

- Take extra care with patients who are confused or who have Alzheimer's disease or other forms of dementia.

The following might be helpful tips:

- Set up a **daily schedule** to make life as predictable as possible
- Consider having the patient wear an ID bracelet if he or she tends to wander
- Keep **medications** out of reach
- Put away **dangerous** items, such as **irons, guns, power tools, scissors, and pins**

Handling Biomedical Waste

"Biomedical waste" (also called "infectious waste") is defined as "any solid or liquid waste that may present a threat of infection to others." **Blood and body fluids** are classified as "biomedical waste" because they have the potential to harbor disease-causing organisms such as human immunodeficiency virus (HIV) and Hepatitis B.

HIV and Hepatitis B can be spread when infected fluids enter the body through:

- needle stick injuries
- cuts, scrapes, rashes, and other breaks in the skin
- splashes into the mouth, nose, or eyes
- sex (oral, vaginal, anal)

Other items or materials that are considered to be **biomedical waste** include:

- Used, absorbent bandages or dressings **saturated** with blood or body fluids that have the potential to drip or splash
- Devices that retain **visible blood**, such as intravenous (IV) tubing, syringes, or catheters
- **Sharps** or other devices capable of puncturing, cutting, or penetrating the skin (these include needles, lancets, intact or broken glass contaminated with blood or body fluids, and intact or broken hard plastic contaminated with blood or body fluids)
- **Urine, stool, sputum, sweat, tears, saliva or vomitus are not considered to be biomedical waste unless they contain visible blood**

When Biomedical Waste, as described above, is produced in your home, your nurse will review the following instructions and provide the necessary supplies to handle it properly.

Instructions for handling biomedical waste

If the waste is **saturated with blood** or with body fluid that contains **visible blood**, place in the red plastic bag provided by Covenant Care. *Examples of biomedical waste: a dressing full of blood or a diaper with bloody urine.*

- Do not overfill the bag; secure when 1/2- 3/4 full, then start another bag
- Do not remove contaminated items from the red bag
- Do not place any other trash in the red bag except waste saturated with blood or body fluid that contains visible blood (deposit other waste **only** as directed by your nurse)
- All other medical waste is to be double-bagged and placed in regular household garbage

Place **"sharps"** (any device that can puncture the skin, i.e. needles, broken glass, or hard plastic contaminated with blood, blood products, or body fluids) in the rigid container provided by your nurse. Contaminated needles are never to be recapped or broken and should be placed in the proper container immediately after use. Needles are never to be re-used. Broken glass or plastics that may be contaminated are not to be picked up directly with hands, but cleaned up with tongs or a brush or broom and dustpan and placed in a rigid container. Do not put Biomedical Waste in the "sharps" container.

Wear disposable gloves when contact with blood and body fluid is likely; wash hands after removing gloves. To clean spills contaminated by blood or body fluids, wear disposable gloves. First wash the area with hot, soapy water, then cleanse for three (3) minutes with a bleach solution of one (1) part household bleach to ten (10) parts water; **remember that the shelf life of the bleach solution is one (1) day.** We recommend that you mix a small amount daily and discard the remaining solution after 24 hours. Wash laundry (linens, towels, etc.) in hot soapy water with one (1) cup bleach to a full load of water (dry on the highest setting).

Always call **Covenant Care** if you have questions about the handling of biomedical waste.

Important Facts to Remember:

- Biomedical waste must never be placed where a child or animal can get into it
- The red bags or containers should never be placed outside the home or on a porch or patio where their contents may become exposed
- Biomedical waste pick-up is not provided to private residences, so please do not place the red bag with biomedical waste at the street curb for collection (this is a violation of established state and federal guidelines and may result in fines or penalties)
- Red bags are for medical waste saturated with blood or body fluid that contains visible blood
- Do not put other medical waste and household garbage into the red bags (double-bag and place in household garbage)
- All sharps, such as needles, go into a rigid container
- Biomedical waste should never be placed in the "sharps" container

Call **Covenant Care** if you have any other questions or concerns..

Alternatives to Restraints

Covenant Care is committed to respecting the rights and dignity of our patients with a restraint-free environment of care, whether in the home, an inpatient hospice unit or in a partner facility. The use of restraints has NOT been shown to successfully prevent injury to patients.

A restraint is any manual method, physical or mechanical device, material, or equipment that immobilizes or reduces the ability of a patient to move his or her arms, legs, body, or head freely. Medication that is not a standard treatment or dosage for the patient's condition is considered a restraint when it is used to manage the patient's behavior or restrict the patient's freedom of movement.

The following are NOT considered restraints:

- Orthopedically prescribed devices
- Surgical dressings or bandages
- Protective helmets
- The physical holding of a patient for the purpose of conducting routine physical examinations or tests
- Methods to protect the patient from falling out of the bed
- Methods to permit the patient to participate in activities without the risk of physical harm

Restraint-free strategies include, but not limited to:

- Providing companionship and/or supervision
- Diversionary and physical activities (e.g., TV, radio, ambulation)
- Reality orientation and psychosocial intervention
- Offering of PRN (as needed) medications to control patient pain, anxiety, or discomfort
- Changing or eliminating bothersome treatments
- Modifying the environment to enhance patient comfort
- Increasing the intensity of nursing care
- Using medical devices to maintain normal body functioning

Helping a Patient Out of Bed

There are times when it may be necessary for you to help the patient get out of bed. Before you try to do this, review the teaching sheet on “Good Body Mechanics” and ask the nurse or aide to demonstrate the correct way to avoid strain as you assist with the transfer. Prepare for the move by placing a wheelchair or a chair with armrests close to the bed. If you are using a wheelchair, remember to **LOCK THE WHEELS** before you begin. If the patient is in a hospital bed, lock the wheels and lower the side rails.

To get a patient out of bed, start by **moving the patient to the side of the bed**. If the patient is unable to move himself, assist him by bending your knees, putting your hands and arms under his lower back, and sliding him to the edge. Pulling, rolling, and turning require less effort than lifting. **Having a “turn sheet” under the patient makes this process easier since you can pull on that instead of the patient.**



Step 1

Pull Patient's upper body
toward you



Step 2

Pull middle of body
toward you



Step 3

Pull legs
toward you

Helping the patient sit up on the side of the bed:

- **ALWAYS TURN YOUR ENTIRE BODY** — do not twist at the waist
- Roll the patient onto his or her side facing you; stand in the front to keep the patient from falling on the floor
- Use one arm to support the patient's neck and shoulder, the other to support under the patient's legs
- Lower the patient's legs off the side of the bed
- Gently pull the patient's shoulders towards you to raise the patient to a sitting position
- Allow the patient to sit up for a few minutes before continuing to the next step so that he or she does not get dizzy (if the patient suddenly loses color in the face or breaks out in a “cold sweat,” these are signs the patient needs to lie back down)

Moving a Patient

From bed to chair, wheelchair or bedside commode:

- **Be sure the wheels are locked if you are using a wheelchair** - position chairs or commodes so that they will not slide while you move the patient
- While the patient is sitting on the side of the bed, and you are directly facing the front of the patient, spread your feet the width of your shoulders
- Position your knees on the outside of the patient's knees on both sides in a "straddle" position
- Keeping your back straight, bend slightly at the knees
- Place your arms around patient's upper chest, beneath the armpits as though you were giving him or her a hug; if possible lock your fingers together
- Straighten your legs to lift the patient
- Turn your entire body when moving the patient — DO NOT twist at the waist
- Slowly lower the patient to the chair by bending your knees

Good Body Mechanics

It is easy to suffer muscle strain or injury while caring for a patient who needs physical assistance or is bedbound. Techniques have been developed in medical settings to use the body to its best advantage. Applying these principles of good "body mechanics" can help the caregiver avoid strain or injury while assisting the patient.

Suggestions include:

- Not moving a patient alone if it is possible to arrange help
- Asking your nurse or aide to demonstrate how to do common things like helping the patient transfer
- Letting the patient know what you are about to do before starting
- Keeping your back straight with knees slightly bent, and lifting from your knees and hips
- Standing with your feet about shoulder width apart with your body as close to the patient as possible to help you maintain your balance
- Using the muscles of the arms and legs to move the patient; avoid using the back muscles as much as possible (encourage the patient to help with movement when possible)
- Do not twist at the waist (turn with your entire body)
- When you are rolling a patient, always pull him or her toward you
- Pushing, pulling, and sliding the patient requires less effort than lifting
- Using a "draw sheet" (aka "turn sheet") to move the patient if he or she cannot assist you with the move (the nurse or aide can show you how this is done)
- Taking short breaks to rest during the move keeps you from getting as tired

Preventing Falls

Falls are the leading cause of injury and premature death among people 65 or older. A large percentage of these occur in the home. Those with a serious illness are particularly liable to fall, even if they are younger. There are many reasons, including:

- Weakness or fatigue due to illness (see “Fatigue and Weakness” section)
- Medications that may cause drowsiness or multiple medications interacting in an unpredictable way
- Problems with balance
- Impaired vision or sense of position
- Tingling or numbness in the feet or hands
- Confusion, which may result in forgetting that help is needed to get out of bed or transfer

Hazardous situations in the environment also create risk for falls. These include:

- Throw rugs or slippery floors
- Poor lighting
- Clutter
- Electrical cords or oxygen tubing in walk areas
- Poorly-fitting shoes or shoes with smooth soles, such as slippers

Covenant Care has a Fall Prevention Program, and we will help assess the risk of falling for all of our patients. We may make a variety of suggestions, including:

- Encourage the patient to sit upright and count to 10 before standing, then stand slowly
- If the patient needs assistance to get up, have a call bell or an attention- getting device handy that he or she can use to get help
- Anticipate that a patient who has limited ability to move around or is bedbound will need to go to the bathroom or become hungry, thirsty, or lonely; offer to help with these things on a regular schedule so that the person has less need to get up without assistance
- Consider using a Covenant Care volunteer during times that the caregiver may need to leave for a short time

For patients who can move around more easily, these things may be helpful:

- Use a cane or a walker and ask for help if you feel unsteady
- Turn on lights and use nightlights in hallways, bathrooms, and bedrooms (keep a lamp or a flashlight close to your bed so you don’t have to get out of bed to turn on the light)
- Install and use grab bars in tub, shower, and toilet areas
- Use nonskid adhesive strips or a mat with suction cups in the shower
- Consider using a shower chair or bench in the shower
- Never leave an unsteady person in the shower or bath area alone
- Consider using an aide (provided by **Covenant Care**) to help with bathing
- Never use bubble bath or shower oil that might make the tub slippery
- Use your glasses and keep them handy
- Remove throw rugs or put “nonslip” material under the rugs
- Wear snug-fitting shoes or slippers that have “tread” on the under-soles
- Remove clutter from walkways and stairs
- Clean up spills quickly
- Consider using an emergency notification system for patients who stay alone

If you or someone in your care should fall:

- Call **911** if there is severe pain or bleeding; and call **Covenant Care** as soon as possible (if you are not sure whether you should call **911** or don't think it is necessary, call your nurse to assess the patient)
- If there is no pain or injury and you feel able, get up with or without your caregiver's help
- If your caregiver is unable to help and neighbors or friends are available, ask them to help
- If help is unavailable, call your nurse or the fire department to assist
- Be sure to tell your nurse about your fall

If a person seems unable to move or get up or is unresponsive:

- **DO NOT** move him or her until the nurse has made an assessment
- Try to make the person as comfortable as possible on the floor
- Cover him or her with a blanket if appropriate
- Question a conscious patient about pain or other symptoms
- Look for obvious signs of injury, such as bleeding
- Apply pressure to control bleeding

Medications like narcotics, antihypertensives, or anticoagulants can increase the risk of falling or the likelihood of an injury. Be sure to discuss possible side effects when starting any new medications.

Fire Safety in the Home

Basic fire safety:

Protect yourself. Prevention is the best way to keep your home safe from fire.

Be kitchen wise:

- When cooking, never leave stove unattended
- Wear clothes with tight-fitting sleeves when you cook
- Always set a kitchen timer to remind you to turn off the burners and oven
- Keep stove surfaces free of clutter and build-up of grease
- Have a fire extinguisher near the kitchen, at least 10 feet away from the stove
- NEVER pour water on a grease fire; turn off the stove and cover the fire with a lid or close the oven
- Keep pot handles turned to the back of the stove
- Do not store items on top of the stove
- Do not overload kitchen electrical outlets, and don't use appliances with frayed or cracked wires
- Do not place a hot plate or other source of heat in front of a window where curtains are hanging
- Keep the exhaust fan and duct clean (wipe up spilled grease immediately)
- Operate the microwave oven only when there is food in it

Be smoker wary:

- NEVER smoke in bed, while using oxygen, while drinking alcohol, or while you are on medicines that can make you drowsy or disorientated
- Wear non-flammable pajamas or night clothes

Give space heaters space:

- Keep electric portable space heaters at least 3 feet from everything — including you. Just brushing against one could set your clothing on fire.
- Do not leave space heaters operating when you are not in the room
- Keep space heaters at least 3 feet away from the wall or anything that might burn
- Do not use extension cords with electrical space heaters (the high amount of current needed could melt the cord and start a fire)
- When lighting a gas heater, strike the match first, then turn on the gas
- Never use a gas range as substitute for a furnace or heater

Install smoke detectors:

- Be sure to have smoke detectors outside all sleeping areas and on every level of your home, including the basement
- Test your detector monthly, and change your batteries once each year
- If you sleep in a room with the doors closed, install a smoke detector inside the room as well
- If you are hearing-impaired, use a tested and approved smoke detector that triggers a strobe light
- Keep smoke detectors clean and dust free
- If your smoke detector is wired electrically, be sure the light is blinking to indicate the alarm is active

Fire extinguishers:

- Fire extinguishers should be in the kitchen, garage and workshop
- Purchase “ABC” type extinguishers for all types of fires
- Learn how to use the extinguisher before there is an emergency
- Remember to extinguish only small fires; if there is a large fire, get out to safety and call 911 from another location

Fireplaces:

- Use a fireplace screen to prevent sparks from flying
- Don't store newspapers, kindling, or matches near the fireplace or have an exposed rug or wooden floor right in front of the fireplace
- Have your chimney inspected by a professional prior to starting a fire at the beginning of the season
- Install a chimney spark-arrester to prevent roof fires

Clothes dryer:

- Never leave home with the clothes dryer running
- Dryers must be vented to the outside, not into a wall or attic
- Clean the lint screen frequently to keep the airway clear
- Never put synthetic fabrics, plastic, rubber, or foam into the dryer, because they retain heat

Electrical hazards:

- It is better not to use extension cords (if you must use one, make sure that the cord is not frayed or worn; DO NOT run it under rugs or wrap or twist it around a nail or hook)
- NEVER overload a socket; do not use multiple plug outlets
- DO NOT use light bulb wattage that is too high for a fixture (look at the label inside the fixture to find the recommended wattage)
- Allow air space around TVs, radios, and appliances

Thinking ahead: your exit plan — be prepared:

- Prepare a floor plan of your home showing at least two ways out of each room
- Sleep with your bedroom door closed; in the event of fire, it helps hold back heat and smoke (if the door feels hot, do not open it; escape out another door or the window)
- Agree on a place outside where you will meet to get a head count
- Stay together away from the fire; call 911 from another location (make sure no one goes back into the burning building)

Infection prevention in the home

Covenant Care is committed to helping our patients and families maintain a safe environment and prevent the spread of infection by providing information and instruction regarding Infection Control, Standard (or “Universal”) Precautions, and cleansing techniques.

Standard precautions and instructions to help prevent the spread of infection

- Good hand washing is one of the most important keys to preventing the spread of infection. Hands should be thoroughly washed with soap and warm water for at least 15 seconds before and after any care is provided to your loved one. Hands should also be washed thoroughly if they become contaminated with blood or body fluids, after gloves are removed, and before preparing or eating food. Recent research has also found that using an alcohol-based rub (a gel, rinse, or foam) is equally effective at reducing bacteria on hands, as long as they are not visibly soiled or contaminated with blood or body fluids.
- Standard precautions assumes that all blood, body fluids, and tissue are potentially infectious. Gloves should therefore be worn whenever there might be direct contact with body fluids (blood, urine, pus, feces, saliva, and drainage of any kind). Unless your nurse has directed you to wear them, gloves are not needed for general care or during casual contact, such as bathing of intact skin, assisting with ambulation, or feeding the patient.
- A moisture-resistant gown or apron should be worn whenever it might be possible to soil clothing through contact with a body substance.
- A mask and protective eyewear should be worn whenever it might be possible for a body substance to splash into the mouth, nose, or eyes.
- Remember to cover the nose and mouth with a tissue when coughing or sneezing. Dispose of tissues in a container or bag that closes. Wash hands after sneezing or coughing.
- Contact precautions may be necessary if the patient has a drug resistant type of infection. These infections could be MRSA (Methicillin-resistant *Staphylococcus aureus*) or VRE (vancomycin-resistant enterococci). These bacteria are very hard to treat and require special medications for longer periods of time. If the patient has one of these type infections, the Covenant Care nurse will instruct you on contact precautions while living with and caring for the patient.
- Contact precautions may include wearing gloves, gown or mask depending on what type of infection the patient has. Your nurse will give you specific instructions related to the patient.

Precautions related to specific activities:

- **Bathing the patient:** Use gloves if open wounds are present and when bathing the rectal/genital area.
- **Bathroom assistance:** If contact with urine or feces is likely, wear disposable gloves and wash hands after discarding gloves
- **Mouth care:** Wear disposable gloves; avoid splattering when brushing teeth.
- **Colostomy and Iliostomy care:** Wear disposable gloves and protective clothing when changing bags; flush waste materials down the toilet; put soiled material (dressings, bags, etc.) in a doubled trash bag and place in the household garbage .
- **Disposal of wastes and sharp items:** Any devices that can puncture the skin are called “**sharps**” (This includes needles, broken glass, or hard plastic contaminated with blood, blood products, or body fluids). They should be placed in the rigid container provided by your nurse. Contaminated needles are **never** to be recapped or broken and should be placed in the proper container immediately after use. Needles are never to be “re-used.” Broken glass or plastics that may be contaminated should not be picked up directly with hands, but cleaned up with a brush or broom and dustpan, or tongs, and placed in a rigid container.
- **To decontaminate or disinfect laundry/linens:** Wash in hot, soapy water with one (1) cup of bleach to a full wash load of water, then dry at highest temperature. **Note:** Household bleach is not recommended for colors; fading and/or discoloration may result.
- **To decontaminate or disinfect surfaces contaminated with blood or body fluids:** Wear disposable gloves and cleanse the area first with soap and water. Use a disinfectant of one (1) part bleach to ten (10) parts water and cleanse surface for at least three (3) minutes. **Note:** Household bleach is not recommended for carpet; fading and/or discoloration could result. Bleach solution should be rinsed off metal to prevent corrosion. The shelf life of the bleach solution is one (1) day. We recommend that you mix small amounts and discard after one day’s use.

Your nurse will be happy to answer any questions or to explain these recommendations in more detail.

Oxygen Safety

Overall, oxygen therapy is extremely safe to use in the home. It has been routinely used for decades in the home care setting. Like any other medical intervention, there are a few safety precautions that should be followed.

Below are tips to keep you safe:

- Oxygen is not in itself combustible; however, it will accelerate a flame and make a fire burn hotter.
- Oxygen should not be used within 5 feet of an open flame (examples: candles, fireplace, wood burning stove, gas stoves, cigarettes, lighters, etc.)
- Patients should never smoke while on oxygen (if a patient must smoke, they need to remove the oxygen source from their face and be without oxygen for at least 30 minutes before lighting up - even though the oxygen may be off the face or turned off, the body and clothing can remain "oxygen rich" for up to 30 minutes)
- Oxygen signage should be posted on entry and exit doors of the oxygen patient's home; this is to alert anyone who enters that there is oxygen being used in the home, but more importantly, it is to alert the fire department, in the event of a fire, that oxygen is in use
- Oxygen cylinders should be stored lying on their sides in a secure place (under a bed, etc.) or in a cart that cannot easily fall over (you must be careful when handling oxygen cylinders that you do not drop them, especially on their "stem." The gas in these cylinders is under pressure and then can become projectiles if they are dropped and broken)
- Do not use petroleum jelly products, grease or any other flammable product around your nose or facial areas
- Make sure that you have working smoke detectors, fire extinguishers and also an emergency fire exit plan

Oxygen Concentrator

An oxygen concentrator is a machine that is used to pull oxygen and nitrogen out of the room air. It separates the nitrogen and discards it. The oxygen is then stored in the concentrator to be delivered to the patient.

- The concentrator has an outer black sponge filter; this filter should be cleaned every 4-5 days with warm water (squeeze dry with a paper towel and replace on the concentrator — ask your nurse to help you with this the first time)
- In the event of a power failure, use your back-up oxygen supplied in the tanks
- The concentrator also has an alarm that will be heard for about 30 seconds when you turn the power on (the alarm should not be heard during operation; if this alarm does not go off, use back-up oxygen and call the DME provider or Covenant Care nurse)
- Do not use oil or grease on oxygen equipment — it's a potential fire hazard
- Never take the unit apart
- Never use extension cords
- Always use a grounded electrical outlet
- Plug unit into its own outlet
- Keep units 12 inches from walls or furniture for proper ventilation and cooling
- Keep units 5 feet from radiators, heaters and hot air registers

Hurricane Preparations

When are hurricanes likely to form?

Hurricane Season starts June 1 and continues through November 30. There is no way to predict how many storms may develop and if they will threaten our area. Currently local and federal disaster agencies recommend you be prepared to survive on your own for 72 hours after a storm or disaster. That's why it's essential everyone have a plan and be prepared.

Hurricane Preparation:

Hurricane preparation for many patients can prevent special challenges and that is why it is very important to have a plan and be prepared should a hurricane threaten our area.

Stock Your Home:

- Water - at least 2 quarts of water per day per person for drinking
- Food - non-perishable, high energy foods to feed your family for up to 7 days
- Supplies - battery operated radio, first-aid kit, flashlight, blankets or sleeping bags, paper plates and disposable utensils, bottle or can opener, toilet articles and sanitary items, extra batteries
- Medications - enough to get by for at least a week
- Extra oxygen tanks, if you use oxygen

Evacuations:

Your plan should include what you would do should an evacuation be ordered for your area. Some things to consider in an evacuation:

- Leave early before roads become crowded
- If you are going to a shelter, let your Covenant Care team know
- Tell your Covenant Care team where you will be going, so they can locate you after the storm
- Don't take more supplies that you can carry; take only what you will need
- If you will need evacuation to a special needs shelter, please talk with your nurse or social worker (they can help you make these arrangements)

After the Hurricane:

- If you have evacuated, local authorities will announce when it is safe to return to the area you live in
- If you are at a special needs shelter, call Covenant Care to assist you in making plans to return to your home
- Assess your home for any structural damage before you go inside or when you are able to safely go outside
- Watch for loose or dangling electrical lines, broken sewer, and water or gas lines; notify local authorities immediately if you see any of these
- Do not drink water from your faucet until officially notified that the water is safe from contamination (use your emergency supply that you stocked prior to the storm)

MANAGEMENT OF COMMON SYMPTOMS

Appetite and Nutrition

Eating is something most of us enjoy, but when we are sick, it may take a special effort. When a person has a life-limiting illness, even though he or she eats an amount that would normally be adequate, weight loss may occur. You may have no interest in food, have difficulty swallowing, food may taste “funny,” or you may suffer from nausea, vomiting, sore throat, diarrhea, or constipation.

These issues can be very upsetting to the patient and the caregiver, who is usually trying to persuade the patient to eat more or fixing special foods with the hope of stimulating the appetite. Since loss of appetite is an expected development of late-stage illness, it is important not to feel guilty if you are unable to eat.

These symptoms may be temporary. Give food another chance when they improve. The following suggestions may also be helpful:

- Eat as much as you want, whenever you feel like it
- Eat whatever appeals to you or looks appetizing (try sampling different types of food to see whether sweet or salty foods taste better to you)
- Avoid strong cooking odors or unpleasant smells
- Give yourself several selections to choose from
- Eat when you feel the best — free from pain and relaxed
- Consider the use of beer or wine to improve the taste of food or increase your appetite
- Don't set impossible goals for yourself

Bloating or early satiety

- Eat small, frequent meals
- Keep snacks or finger foods handy
- Eat slowly
- Sit upright when eating
- Eat easily digestible foods (avoid fatty foods & gas-forming vegetables)
- Drink fluids between, rather than with, meals

Chewing problems

- Modify food consistency, going from soft to ground to pureed, based on severity of problem
- Moisten foods
- Emphasize soups, stews, cooked and cold cereals, eggs, custards, puddings, and liquids
- Chop, mash, or strain cooked fruits and vegetables
- Try baby foods-- alone (spice to taste) or added to soups and broths

Taste alterations (ageusia)

- Experiment with new flavors and foods
- Try stronger flavors such as lemon
- Use condiments on chicken, meat, and fish
- Drink or rinse mouth with carbonated water, ginger ale, or tea after meals to help get rid of bad tastes

Viscous or thick saliva

- Milk and milk products may cause increased phlegm production (try low-fat or soybean milk products, or use ginger ale or club soda to “cut” milk and shakes)
- Clear liquids, broths, hot tea with lemon, popsicles, lemonade, carbonated beverages, sherbets, and ices may be better tolerated than thick liquids (commercial clear liquid high-calorie protein supplements are available)

Tube Feedings

Tube feedings are sometimes given when the patient is unable to take in adequate food or medications by mouth. The tube may be placed through the nose and down into the stomach (NG-tube) or directly through the skin into the stomach (G-tube) or intestines (J-tube).

Tube feedings may be given by pump or by gravity flow. If you use a pump, your nurse will teach you how to operate it.

Things to Remember About Tube Feedings:

- Always wash your hands before handling feeding or equipment
- The feeding tube should be flushed with water before and after each feeding (use the syringe your nurse supplies)
- Feedings should be given at room temperature
- Never force food or medicine through the tube (if the tube seems to be blocked, try to flush the tube with water; if unable to flush, notify your nurse)
- Store the feedings as instructed by the pharmacy or nurse
- Never let feedings hang for more than 8 hours unless they are part of a “closed system” (these are meant to hang for up to 24 hours; your nurse will give you specific instructions)
- Change the feeding bag and tubing every 24 hours
- If the patient complains of fullness or vomits, stop the feeding and call your nurse
- The patient should stay in the sitting position (raise the head of the bed to a comfortable “sitting” position) during feeding and for 1 hour afterwards, if at all possible
- If the tube comes out, don’t panic — call your nurse

Breathing Problems

Not being able to catch your breath can be a frightening feeling. Lung disease, pneumonia, anxiety, or fluid in the lungs may make it difficult to breathe easily. Problems can include chest pain, wheezing, pale or bluish skin color, sweating, a rapid pulse or rapid breathing rate.

If breathing difficulties occur:

- **Remain calm.** Although it is normal to feel anxious when someone else is having problems breathing, caregiver anxiety can make the breathing difficulties worse.
- **Elevate Head of Bed**

Also try these options:

- Lean forward with hands on your thighs
- Give medications as instructed by your doctor or nurse
- If oxygen is being used, make sure it is running properly and there are no kinks or knots in the tubing
- Lower the thermostat, as it is easier to breathe in a cooler room
- A fan gently blowing directly on your face may also help
- Encourage slow, deep breathing, taking air in through the nose and blowing it out through the mouth as though blowing through a straw (exhaling fully by blowing out all possible air before taking in a breath prevents carbon monoxide from building up in the lungs and making breathing even harder)
- Call your nurse if symptoms do not resolve or if you have questions or concerns

Broken Bones, Fractures

Certain conditions and diseases, such as severe osteoporosis or cancer that has spread to bone, can cause a person's bones to weaken and or become so brittle that they break more easily. Sometimes they even break spontaneously, without apparent cause. These breaks are called "pathological fractures."

Signs and symptoms

- **Increased pain, usually in one place (pain may be described as a feeling of pressure or as a sharp or continuous dull aching; it is often worse when the person moves)**
- **Swelling at or near the site**
- **Deformity or misshapen body part (when a fracture happens to the upper leg and hip, one leg may be shorter or one foot may turn out)**

If you think there is a fracture, try to remain calm. If possible, stabilize the body part, with pillows on each side to restrict movement and ease pain. Call Covenant Care and report your symptoms as soon as possible.

Cardiac Disease, End-Stage

End-Stage Cardiac disease can cause many distressing symptoms. Hospice care is provided to improve your quality of life by controlling those symptoms. Most types of heart disease are chronic in nature and symptoms are relieved with medications. Over time, these medications may not be tolerated as well, and it may be necessary to adjust or change them.

Medications to control symptoms may include: stool softeners, oxygen therapy, pain medications, anti-anxiety medications, and anti-angina medications. Your nurse will review these with you. It is important that you take them as ordered to keep symptoms under control.

If you have any other questions or concerns, be sure to ask your nurse.

The following things are also helpful in managing symptoms of End-Stage Cardiac:

- **Conserve your energy by resting between activities**
- **Monitor your weight gain**
- **Elevate the head of the bed**
- **Elevate legs and feet**
- **Decrease sodium levels** **ng sound may be heard if the person moves the body part**

Confusion, Agitation, Anxiety, Restlessness

It is not uncommon for those who are at the end of life to experience restlessness, confusion, anxiety, or even agitation. These symptoms can appear quickly, and you may be surprised by your loved one's actions.

- Your loved one may try to get out of bed, even though he or she is physically too weak to move.
- Facial expressions and body posture that let you know the patient is uncomfortable, restless, or fidgety.
- Your loved one may yell at others and use uncharacteristic language.
- Your loved one may become physically restless or agitated. At this time, your loved one may not be objective about his/her condition and may need your help.
- Your loved one may also see or hear things that are not there. Try to discern if he/she is frightened by the images or sound. If your loved one is frightened by the hallucinations, it is a good time to call the hospice nurse.
- Sometimes, those who are dying "see" people that have already died. This can be a source of great comfort.

Causes include:

- Disease progression
- Decreased oxygen to the brain
- Tumor spreading to the brain or the fluid around the brain
- Constipation/full bladder
- Intense pain
- High fever
- Certain medications
- Unfamiliar surroundings

Caring for someone with these symptoms:

- Speak softly and gently.
- Turn off the television while talking or when the person is sleeping.
- Talk slowly, using short, simple statements (always face the person when you speak).
- Identify yourself.
- Stay within a few feet of the person while talking (if appropriate, use touch).
- Play soft, soothing music, and keep the room lighted when appropriate.

- Explain what you are doing step by step when assisting with dressing and bathing.
- Notice the person's eating habits, since they may forget to eat or have problems chewing or swallowing.

Considerations to discuss with care team:

- The physical comfort of your loved one.
- The environmental comfort of your loved one — be aware of noises, temperature, people or things that may be aggravating to your loved one.
- How to help manage your loved one's pain and symptoms.
- Changes in breathing and oxygen levels may make your loved one feel anxious. The physician may order oxygen to help relieve these symptoms.
- When was your loved one's last bowel movement? When did they last urinate? Does your loved one need a urinary catheter? If they already have a catheter, is it blocked?
- Is your loved one showing signs of a change in mental status? Is he or she more confused than the last time your hospice nurse visited?
- Is your loved one fearful about dying or have unresolved business? If so, a social worker and chaplain are available to your family to assist.
- Did your loved one recently start a new medication, stop a medication or change dosage?
- Is your loved one declining or showing signs and symptoms of approaching death?
- Your hospice team may need to use medications to address these symptoms in your loved one. Some of the medication choices may include: Lorazepam (Ativan), Diazepam (Valium), Haloperidol (Haldol), and others.

To help protect from injury:

- Don't leave the person alone for long periods of time.
- Help the person to the bathroom or with activities of daily living.
- Avoid leaving medications within reach.

Cough and Congestion

Coughs and congestion are often due to a common cold or an allergy, but sometimes may indicate an infection in the lungs or progression of a disease. Prolonged coughing can cause fatigue and discomfort.

- **Dry coughs** - cough suppressants or anti-tussives curb the body's urge to cough
- **Productive coughs** (those that produce phlegm) are treated with expectorants to loosen mucus in the respiratory tract
- If a new cough or congestion appears in a hospice patient, it is best to call the nurse so the patient can be evaluated

Call your Nurse if cough and congestion are accompanied by:

- Fever
- Chills
- Coughing up yellow or green sputum
- Tightness in the chest
- Change or difficulty with breathing

Some ideas to discuss with your care team to assist with these symptoms:

- Fluids to help thin secretions
- Placing a vaporizer or humidifier in the room
- Elevating the head of the bed

Deep Breathing and Coughing Exercise:

Deep breathing combined with coughing is one way to bring up mucus. Breathe deeply through your nose to fill your lungs, hold for 2-3 seconds, exhale through pursed lips and repeat 2-3 times. The last time, cough forcefully out of your open mouth, taking care to cover your mouth with a tissue (to help prevent the spread of germs).

Diarrhea and Constipation

A normal bowel movement is different for each person and may vary in consistency and frequency. Keeping your bowels working regularly can be a challenge when you are ill. Decreased activity, decreased food and fluid intake, medications, infections, and sometimes the disease process itself all have an effect on the bowels. Your hospice nurse and physician will adjust medications for your bowels as needed to keep you comfortable.

Contact your hospice nurse if you have:

- More than 6 bowel movements a day for more than 2 days
- Blood in your stool
- Severe cramping or a fever
- No bowel movement for 3 days
- Any other bowel concerns

Diarrhea

- More than three bowel movements per day, liquid bowel movements, with or without discomfort
- Caused by water in the intestine not being reabsorbed into the body for some reason, possible impactions (liquid flows around a blockage of stool), medications or laxatives, infection, supplemental feedings, tumor growth, or side effects from chemotherapy or radiation
- May last several days after radiation treatments

To control diarrhea and its complications:

- Consume foods high in protein and/or low in fiber:

Cottage cheese	Applesauce
White rice	Pasta
Bananas	Baked potatoes
Cooked cereal	White toast
- Nutmeg added to food slows down the movement of stool in the intestine
- Drink clear liquids, such as water, fruit juices, re-hydration drinks like Gatorade, and broth (if diarrhea lasts for more than 48 hours, notify your nurse for instruction)
- Clean rectal area with mild soap and warm water after each BM, rinse well and dry, then apply water-repellant salve to the area, such as A&D Ointment or Desitin
- Warm tub baths help relieve the discomfort of rectal irritation

Things to AVOID include:

- Caffeine products (colas, coffee, or teas)
- Alcohol
- Milk or milk products
- Very hot or very cold liquids
- Tobacco products

Constipation

- Change in normal bowel movements (less frequent, smaller, drier, harder, or more difficult to pass)
- Causes include: decreased activity, decreased food and/or fluid intake, some medications, or the disease process itself

The following things may be helpful in treating or preventing constipation:

- Warm prune or fruit juice
- Fresh fruits with skins
- Fresh vegetables, especially raw, green and leafy vegetables
- Whole wheat or bran cereal and breads
- Increased water intake
- Increase in your activity level as your condition permits

Be sure to take the medications your doctor has ordered, as they will help prevent constipation and impactions (stool that sometimes needs to be manually removed). Your nurse will help you identify medications that may complicate regular bowel movements and will work with your physician to set up a system to prevent constipation if you are taking a medicine with this side effect.

Fatigue and Weakness

Fatigue and weakness frequently occur as symptoms that interfere significantly with the quality and enjoyment of life. Sometimes these seem connected to disease progression, but other factors such as poor nutrition, anemia, depression, or side effects of drugs and treatments (radiation therapy or chemotherapy) may contribute.

Some indicators of fatigue and weakness:

- Decreased energy and difficulty performing routine activities of daily living, such as bathing, dressing, eating
- Increased desire to sleep, with decreased interest in activities
- Episodes of falling (with or without injury)

Some helpful ways to control fatigue and weakness include:

- Conserve available energy by spacing activities and resting frequently.
- Do some things you enjoy each day (pleasure often creates extra energy).
- Space out tasks and activities that are most tiring.
- Ask your nurse about supplements or nutritional “boosters” that might give you more energy.
- Use a relaxation practice such as “Quiet Breathing” or “Full Body Relaxation” to restore energy.
- Request an aide or volunteer to help with your tiring tasks.
- If you are unsteady on your feet, have someone walk with you to provide stability and to help you from falling.

Ask your social worker about community resources that support independent living (Meals on Wheels, Emergency Alert Systems, etc.) and your nurse about assistive equipment that may be helpful (wheelchair, shower chair, etc.). Discuss your worries and concerns with a friend or a member of your care team, such as a social worker or chaplain (emotional distress can drain physical energy).

Fever, Sweating and Infection

Fevers are sometimes a sign that the body has an infection, but they can also be caused by the body's reaction to cancer. These are called "Tumor Fevers." At times, hormonal changes can cause heavy perspiration or sweating, but usually without actual fever.

To relieve symptoms and discomfort of fever and help prevent or treat infections, the following are helpful:

- Take medications prescribed by your doctor for fever or infection.
- Apply cool washcloths to the forehead, axilla (underarms), and/or neck to help cool patient.
- Follow your nurse's instructions for any dressing changes.
- Use lightweight cotton clothing and bed linens when possible.
- Change wet clothing or bedding as soon as possible.
- Drink cool liquid if able.
- Eat high-calorie, high-carbohydrate foods like bread, pasta and fruits (this may help replace lost energy and nutrients).
- Keeping skin intact will help prevent germs from entering the body through cuts and skin tears.
- Ask visitors who have colds or infections to wait until they are better to visit.
- Patient and caregivers should wash hands frequently.

Sweating is one way the body attempts to cool itself off. People also perspire in response to activities such as exercise, or emotions, such as fear. Certain medical conditions and/or medications may cause excessive sweating.

Infections can develop in any area of the body, both inside and out. White blood cells are the body's natural defense against infection. Some treatments for disease, such as chemotherapy, lower the white blood cell count. This increases the risk of infection. Common signs of infection include swelling, redness, pain, and fever.

More specific signs of infection are:

- Oral temperature of 101 degrees or higher that does not respond to an antipyretic (fever reducer) such as acetaminophen (Tylenol)
- Severe, shaking chills that last 20 minutes
- Frequent, painful urination
- No urine output for 6 to 8 hours
- New cough, shortness of breath, or rapid breathing

If you are concerned about any of these symptoms, call the nurse so the patient may be further evaluated.

Hiccoughs (“Hiccups”)

Having the hiccoughs can be very tiring and distressing. Hiccoughs are usually caused by an irritation of a nerve in the chest or neck or by stomach enlargement from gas, food or tumors. Some medications can cause or worsen hiccoughs. Listed below are some measures which may help stop hiccoughs. If these do not work, your nurse will assess you and may call your doctor to get a prescription drug to try to stop your hiccoughs.

Suggestions that may help stop hiccoughs:

- Drink peppermint water or suck on a peppermint candy
- Hold your breath while looking up to the ceiling
- If you can tolerate it and are not diabetic, eat a large spoonful of dry granulated sugar
- Re-breathe into a paper bag
- Tickle the inside of the nostril or the back of the throat with a Q-tip swab
- Drink pineapple juice or suck on a lemon wedge
- Drink a glassful of water quickly, 10 small swallows without taking a breath
- Chew and swallow dry toast
- Pull on the tongue to stimulate a gag reflex
- Drink water from the opposite side of the glass

If you have excess “gas” that may be causing your hiccoughs, discuss with your nurse medications to alleviate this symptom.

Hydration and Dehydration

Adequate hydration is very important if we want to remain healthy. It increases circulation, provides muscle tone, and decreases constipation. We hydrate our bodies by drinking liquids such as water, soups, milkshakes, fruit juice, tea, or coffee. When a person has a life-limiting illness, it is often difficult to maintain an adequate fluid intake. This is distressing to loved ones and often leads to the question of whether we should provide fluid by artificial means.

As a disease progresses, body systems begin to slow down, and patients typically have less desire to eat and drink. In addition, the body has a harder time processing food and drink because it is no longer working efficiently. Recent research shows that as the body begins to dehydrate, it releases its own natural painkillers. At this final stage of life, dehydration is beneficial and eases suffering, making the dying process easier.

To introduce fluids artificially at this time may overtax the body’s heart, lungs, and kidneys, which are not working well. It may also increase swelling, vomiting, and lung congestion. IVs are not always beneficial or recommended, because they may also increase fluid overload. Frequently, IVs only prolong life for a short time, without improving comfort or quality of life.

Dehydration can occur whenever there is inadequate intake of fluids or excessive fluids are being lost from the body. Causes may include loss of appetite, difficulty swallowing, nausea or vomiting, diarrhea, use of water pills, or excessive sweating.

Skin may become dry or flaky, membranes in the nose and mouth may be sticky, lips may crack, and urine may be darker and strong smelling, with a decrease in amount. Your loved one may become very weak and seem confused.

What’s important at this stage is to focus on relieving any uncomfortable symptoms. Good mouth and skin care are especially important and are described in the appropriate sections of this guide.

Incontinence

Frequently in the course of a life-limiting illness, the patient loses bowel or bladder control, and this is called, "incontinence." Since it often occurs during the dying process itself, we are often not able to correct it. We manage incontinence by using disposable adult briefs, diapers, or pads placed under the patient who is bedbound. Occasionally, we may discuss with the physician inserting a urinary catheter, especially if difficulty keeping the patient dry is causing other problems like skin breakdown.

Adults become incontinent of urine for many reasons, including:

- **Functional Incontinence:** person has normal urine control, but cannot get to the bathroom in time because of illness
- **Overflow Incontinence:** occurs when the bladder is always full, so a small amount leaks out (this can be the result of an enlarged prostate in men or can happen to some people with diabetes)
- **Stress Incontinence:** occurs when a person coughs, sneezes, or laughs (these activities put pressure on the bladder and cause a leakage of urine)
- **Urge Incontinence:** inability to hold urine long enough to reach a toilet (may be related to a urinary tract infection, medications that relax the bladder such as tranquilizers, or medications that increase urination such as diuretics; most often it is caused by medical problems and sometimes has to be accepted as a permanent condition of the disease)

Adults are often embarrassed when they have accidents. It is helpful if the caregiver can be understanding and can avoid placing blame. Incontinence can cause skin irritation and increase the risk of developing bedsores. It is important to maintain good skin care. Be sure to talk to your nurse about preventive options.

Insomnia

Insomnia includes difficulty falling asleep, difficulty staying asleep, or a poor quality of sleep or not feeling rested: it occurs for a variety of reasons including pain, nausea, anxiety, depression, coughing, and other uncomfortable symptoms. Some medications can cause it as well. It is important to address the issue because lack of sleep tends to exaggerate the effects of pain and other symptoms.

Insomnia results in:

- Daytime fatigue
- Increased risk of falls
- If the caregiver is unable to sleep, this increases the difficulty of providing empathic care for the patient
- Cognitive impairment
- Decreased quality of life

Ways to get a better night's sleep include:

- "Wind down" at the end of the day (as bedtime approaches, minimize conversation, challenging tasks, and excitement or upset).
- Go to bed and get up at the same time every day; this allows your body to establish a rhythm or routine.
- Take a warm bath and follow with gentle massage to back, hands, or feet.
- Drink a glass of warm milk or a cup of chamomile tea.
- If any of your medications are sedating, try to take at bedtime.
- Take medications prescribed to help you sleep at a regular time.
- If any of your medications have stimulants, you might want to take them earlier in the day if possible (discuss with your nurse).
- Sleep when you are tired or feel sleepy (when awake and able, do simple activities or things that are of interest such as reading or hobbies).

- Keep bed linens clean, neatly tucked in, and free of wrinkles.
- Do not drink caffeinated beverages (coffee, tea, cola), or eat foods such as chocolate, late in the day.
- Do not ignore pain; take your medication as ordered for pain.
- If you are worried or anxious, try talking to someone you trust about your concerns.
- Do not take any medication for sleep other than that ordered by your doctor.

Mouth Care

Good mouth care is important to maintain quality of life. Most of us take for granted the ability to speak, the pleasure of eating, and the normal handling of saliva. Good oral care becomes even more important for the person who is seriously ill, because keeping the mouth clean may help to prevent such complications as aspiration pneumonia, which may occur when a “foreign” substance is inhaled into the lungs. When people are severely ill, they often do not swallow as often, saliva may accumulate in the mouth, and the patient may inhale saliva with bacteria resulting from poor oral care. There are many other conditions that can occur as a result of poor mouth care, with infections and pain as the end result.

While doing mouth care, always look in the mouth for signs of sores or reddened areas. Mouth care is usually done morning, evening, after meals and whenever needed.

Mouth care supplies:

- Toothbrush or a toothette, which is a pink sponge on a lollipop-type stick that your aide can give you
- Toothpaste, if patient is able to spit it out when finished
- Basin to spit into
- Face towel to protect patient's clothes
- Place patient on his or her side when possible
- Place towel under patient's face
- Wet toothettes with either cool water, gentle mouthwash (avoid alcohol-based, as these are too drying), liquid saliva (can be bought from a pharmacy)
- Gently place toothette in patient's mouth and cleanse teeth, tongue, and mouth area (change toothettes whenever needed, throwing away used ones)

Mouth care for a bedridden person who can brush his or her own teeth:

- Help the patient to an upright sitting position
- Place towel around patient's neck
- Wet toothbrush and put toothpaste on it for the patient
- Help patient hold the basin while rinsing mouth out with water

Mouth Care for a bedridden person who cannot brush his or her own teeth:

- Mouth care may need to be done more often
- Wash your hands before starting mouth care (this helps to prevent spreading germs)

For dry mouth:

- Use small amounts of water or ice chips
- Moisten a clean washcloth with water for the patient to suck on
- Swab mouth with toothettes soaked in water
- Keep lips soft and moist with lip gel or balm
- Increase fluids whenever possible
- Use a humidifier

Muscle Spasms and Leg Cramps

Involuntary and often painful contractions of the muscles are sometimes called a “charley horse.”

Possible Causes:

- Lying in bed for long periods of time, causing muscles to cramp
- Pressure on the calf muscles or on the back of the knee
- Dehydration
- Lack of calcium or potassium in the diet
- Try walking around or pointing the toes toward your nose
- If you are not on a restricted diet, include foods and drinks which are high in calcium and potassium, such as milk, hard cheese, greens, bananas, strawberries, orange juice, fruits, shellfish and tonic water
- Avoid getting too tired or too tense

These things may help:

- Stretch your legs and change your position in bed often (avoid positions that put pressure on the back of the knee or on the calf muscles)
- Learn about proper positioning from your nurse or aide
- Exercise the legs by slowly bending and straightening several times (a family member can help move the leg if it is difficult to do it alone)
- Apply moist heat to the leg during a spasm
- Stay warm

Contact your nurse if:

- Cramping is not relieved by the steps listed above
- Cramping continues for more than 6-8 hours
- The cramped leg or foot becomes red, swollen or hot, or if pain is unrelieved

Your doctor may prescribe a muscle relaxant or other medication if the cramping persists.

Nausea, Vomiting and Dry Heaves

Almost everyone has had an upset stomach and would agree it's something they prefer to avoid. Although nausea, vomiting, and dry heaves sometimes occur in life-limiting illness, they are usually temporary and can be successfully treated. Symptoms may be caused by the disease process, which slows down or interferes with digestion, by strong odors or unpleasant smells or by some treatments or certain medicines.

- Slowly consume small amounts at a time
- Chew food thoroughly
- Have whatever is most appealing, whenever you feel like it
- Try cool, clear liquids such as “Gatorade” and carbonated drinks that have been stirred or left sitting to become “flat”
- Avoid drinking liquids while you are eating (this can cause you to feel too full)
- Suck on mints, ice chips, or hard candy
- Take slow, deep breaths
- After eating, rest with your body in a semi-reclining or sitting position
- Eat dry foods like toast, crackers, or raw oatmeal in small bites in the morning
- Avoid fried or fatty foods (they are more difficult to digest and leave the stomach slowly)
- Eat high-carbohydrate foods like as crackers, Jell-O, toast, and juices (they leave the stomach quickly)
- Avoid strong/offensive odors (even “normal” cooking odors maybe too strong)
- Open containers away from you so that odors drift away instead of directly into your face
- Take your medicine for nausea 30 minutes before eating

Pain Control

Pain and its control is a primary focus of hospice care. The term to describe this kind of care is “palliative care,” which addresses all the needs of the person with a life-limiting illness and strives for the highest possible degree of comfort, peace, and dignity. We especially believe that every patient has a right to adequate pain control, and we work hard to achieve the level of comfort the patient and family wish to have. Most Covenant Care patients report their pain is controlled within 48 hours of admission to our program. The following information is an overview and may answer some of the questions you have, but if you have a concern not addressed here, please ask your nurse or social worker.

*****All medication must be kept in a safe place out of the reach of children.*****

Reporting pain

All members of the hospice Interdisciplinary Group evaluate for pain. They will ask you frequently, “On a scale of 0 to 10, how much pain are you having, with ‘0’ being ‘no pain’ and ‘10’ being ‘the worst pain you can imagine?’” Our staff will keep track of your pain and collaborate with your doctor on any adjustments that may be needed to keep you comfortable.

Occasionally patients don’t want to “complain” or “inconvenience” staff by saying that they have pain. Some might feel that they should be strong enough to tolerate the pain; others might feel the pain is a “punishment” for things that have happened in the past. These feelings are normal, but rather misguided. We try to control pain so instead of using energy on fighting pain, patients can use that energy to do things that will improve their quality of life. If you have any concerns about reporting your pain, we urge you to discuss them with a member of your care team.

Pain medication and addiction

Some patients are concerned that they may become “addicted” to the pain medication. There is a difference between being “**physically dependent**” and having a “**psychological**” addiction.

Narcotic addiction is being dependent on the regular use of narcotics to satisfy physical, emotional, and psychological needs, not for a legitimate medical reason. The medical reason for taking narcotics is pain relief. If you are prescribed and take narcotics for pain relief, you are not an “addict;” it does not matter how much or how frequently you take these medications.

Taking pain medication:

Studies have shown that the most effective way to take pain medication is “by the clock.” This means that you take the medicine regularly, rather than waiting until you have pain. These medicines are often “time released” and put a uniform level of pain medicine in your system over an extended period of time. This means that less medication can be used to control the same pain.

Before crushing any pain medications, be sure to check with the nurse. Do not give extra doses of pain medication without checking with your nurse.

In addition to your regular dose of medicine, your doctor may order faster-acting pain medicine for “breakthrough” pain. This is pain that occurs in between the regular doses of medicine. An example of this may be the patient who takes regular pain medicine and is very comfortable while sitting, but has additional pain on getting up. The faster-acting pain medication will help to control the pain with movement, and would probably be taken just before getting up to do any activity. It is important that every time you use this faster-acting pain medicine, you write down the time and the amount of medicine. Your nurse will report this to your doctor, who will use this information to adjust your routine pain medicine.

Enhancements to help control pain:

Sometimes pain control can be improved with non-drug methods. We encourage you to try these methods and to discuss the results with your nurse and social worker.

- **Distraction or diversion** – Many people with chronic pain find these methods help control their pain. The idea is that if you think or concentrate on something besides the pain, the pain may lose some of its power. Some examples are: watching TV or movies, particularly humorous ones; reading; visiting or talking with a friend on the phone; listening to music, writing, painting or any other activities that you enjoy.
- **Meditation and relaxation** – Discuss with your nurse or social worker.
- **Massage** – Sometimes massaging the muscles and helping the body relax will help to ease the pain. This should always be started gently, using an oil to prevent friction on the skin. The patient should give feedback as to whether or not it is helping.

Hot and Cold Packs

The use of heat and/or cold has long been recognized in symptom relief. At some point, your doctor may order either a hot pack or a cold pack for an area of the body. The following are some simple instructions for the safe use of both, which will help prevent an injury from their use. Before using, be sure to discuss with your nurse.

Making a moist heat pack in the microwave:

- **Purpose of using heat:** To provide pain relief, promote muscle relaxation, relieve muscle spasms, and increase blood flow to area

Materials: One large Ziploc freezer bag, two large bath towels

What to do:

- Run the towel under warm tap water and wring towel out
- Fold towel and place in OPEN Ziploc bag
- Place bag in microwave oven set on "high" for two minutes
- Remove hot towel pack from oven and bag
- Wrap hot towel with dry second towel
- Cover body part with toweling to avoid burns, while keeping the area as warm as possible
- Leave on body a maximum of 20 to 30 minutes

Making a slush cold pack:

Purposes: To relieve pain, to decrease swelling

Materials: One large Ziploc freezer bag, rubbing alcohol, water, two large bath towels

Method:

- Mix three cups water and one cup alcohol in Ziploc bag
- Remove as much air as possible and seal bag
- Place mixture overnight in freezer
- Place towel between body part and pack to allow skin to adjust to the cold gradually
- Conform cold pack to shape of body part and cover with an additional towel
- The cold will not freeze your skin when properly applied
- Treatment time is usually 10 to 15 minutes, or to your comfort for a maximum of 15 minutes

Caution - Do not use packs if you have an undiagnosed or contagious skin disease, you are overly sensitive to hot or cold, or the area to be treated has been frostbitten at any time.

If any unexpected reaction occurs, call the hospice nurse immediately.

Seizures

A seizure is the involuntary and uncontrolled movement of muscles, usually lasting less than 5 minutes. Seizures can be followed by loss of consciousness, periods of sleepiness, and confusion that can last several hours. Although they may be very frightening, they can occur for many different reasons, all of which can be managed:

- High fever
- Infections in the spinal fluid
- Metabolic imbalance
(low sodium, very low sugar)
- Tumor growth in the spine or brain
- Adverse reaction to medication

What to look for:

- Jerking movements of body, especially arms and legs
- Eyes rolling back or blank stare
- Suddenly losing ability to control bladder or bowel

What to do:

- Stay calm and remain with the patient.
- Ensure patient safety (put side-rails up, and pad rails with pillows, blankets, or towels)
- Keep the patient from falling by easing him or her to the floor or cradling the patient in your arms
- Place padding under the patient if possible
- Place a roll of towels, clothing, or small pillow under patient's head and roll or tilt head to the side; roll patient onto side so secretions such as mucus will run out of the mouth if the patient is unable to swallow
- Loosen tight clothing around the neck
- Notice the kinds of movements, such as hard jerking or stiffening of body parts, and how long the seizure lasts
- When the seizure is over, cover the patient with a blanket and allow patient to rest
- If the patient is prone to seizures, pad bedrails any time they are raised (be cautious with leaving bedrails up, as it is possible for the patient to become entangled in them and get hurt)
- Administer anti-seizure medications regularly, if prescribed
- Do not leave the patient alone during a seizure
- Do not forcefully turn any rigid body part such as neck, arm, or leg
- Do not restrain or try to stop the patient's movements
- Do not move the patient, except as instructed above, unless patient is near a dangerous object such as glass, heater or radiator, or stairway
- Do not put your fingers near the patient's mouth, and don't try to open the mouth
- Do not give food, liquid, or medicine until the patient is fully awake
- After the seizure is over and the patient appears safe and comfortable, call your nurse to report the seizure (your nurse will notify your doctor as necessary and will give you additional information or instructions if needed)

Skin Care

Our skin is the body's largest organ. It protects our internal organs, bones and muscles, regulates body temperature, and protects us against fluid loss. Basic skin care does not change because you are ill. Regular hygiene such as bathing or showers, shampoos, and lotion for dry skin should continue.

Weakness, poor appetite, and fatigue can all contribute to decreased movement. Sitting for long periods of time or staying in bed most of the time requires special skin care. Should you have any questions or concerns about skin care, be sure to ask your nurse.

Preventive skin care

- Keep the skin clean and dry
- Change pads or adult briefs soiled with urine or stool as soon as possible
- Gently wash the genital area with mild soap and rinse with water
- Keep dry, flaking skin lubricated with creams or lotions
- Skin-to-skin contact areas (between legs, under breasts, in folds of abdomen) can cause perspiration and irritation (dry these areas thoroughly; a light dusting of baby powder or corn starch may help keep these areas dry)
- Be sure to turn and position the patient frequently (your nurse and aide can teach you the proper ways to do these)
- Check the skin for reddened areas (look especially at heels, elbows, buttocks, the back of the head, ears, lower back, and shoulders; notify the nurse if you notice any changes in skin integrity)
- Avoid the use of scented soaps or lotions and harsh laundry detergents
- Apply unscented lotions or emollients to skin
- Keep nails short and trimmed to prevent damage to skin (keep hands clean - this applies to both the patient and the caregiver)
- To increase comfort, try cool baths with baking soda and use medicated lotions or gels as recommended by physician or nurse
- Use cotton clothing when possible
- Frequently change the bedding to keep dry, especially if patient perspires or sweats a lot

Itching skin

Itching is an unpleasant sensation of the skin, causing you to scratch or rub the skin. Itching may be due to dry skin, allergies, side effects of medications, chemotherapy, or radiation therapy. Look for: dry, red, rough flaky skin, rashes, scratch marks, skin sores, skin with yellow color, scratching without thinking about it. Be sure to report itching to your nurse, who may seek additional instructions from your doctor.

To help ease the discomfort of itching skin:

- Cleanse the skin gently, using a mild soap
- Use warm, not hot, water for bath — add baking soda or treatments such as Aveeno to bath water (avoid oils in bath because of risk of falls)
- Apply soothing skin lotions
- Apply skin creams 2 to 3 times a day
- Apply a cool pack to the skin
- Keep nails clean and clipped or filed short (hands can also be covered with socks to prevent scratching skin)
- Dress in loose clothing made of soft fabric (cotton or flannel)
- Change bed linens daily, if patient is bedbound
- Keep the room cool and well ventilated
- Drink plenty of fluids
- Check with your nurse about an over-the-counter medication such as Benadryl that may be helpful
- Try to keep your attention away from scratching by watching TV, reading, or visiting

Bruising and Bleeding

Normal disease progression, and some drugs used in chemotherapy and radiation therapy treatments, may temporarily decrease the number of platelets in the blood. Platelets help to clot blood, prevent bleeding, and promote healing. If the platelets are low, you may bruise more easily or bleed more often and for longer than usual.

What to look for:

- Bruises – Small red spots under the skin
- Cuts or wounds that bleed longer than usual
- Blood in urine or stool, bleeding gums, nosebleeds
- Report any bleeding to your nurse (if bleeding seems excessive or different from bleeding episodes in the past, call Covenant Care immediately)
- Avoid hot, stiff, or rough food that may scratch or irritate your mouth, such as dry toast or raw apples
- Do not take aspirin or products containing aspirin without your doctor's consent
- Shave with an electric razor
- Use increased caution with sharp objects such as scissors or clippers
- Avoid enemas, suppositories, harsh laxatives, and douches (don't take a temperature rectally)
- Use a stool softener on a regular basis
- Avoid excessive straining when moving in bed or having a bowel movement
- Avoid blowing your nose forcefully
- If a nosebleed occurs, sit up straight and apply firm pressure to the nostril area below the bridge (area that glasses sit on)
- If the nosebleed doesn't slow down in a few minutes, place an ice bag on bridge of nose and the back of the neck

To help prevent bruising or bleeding:

- Clean your teeth gently, using a soft toothbrush (when bleeding does occur, rinse mouth with cold water, unless there are swallowing problems)
- If excessive bleeding occurs in the mouth, use cotton swabs or toothettes to clean teeth (avoid dental floss and water picks at this time)
- Rinse your mouth, if you are able, with a normal saline solution of 1 teaspoon of salt in 1 quart of boiled, cooled water

Call your nurse if bleeding is excessive or nosebleed continues longer than 10 minutes.

Skin Pressure Sores

Persons who are bedridden or sit for long periods of time put pressure on the same places, making these areas more likely to develop sores. To help prevent this problem, changing positions is very important. Pressure damage also happens faster if the skin is rubbed or pulled against the sheets or other surfaces on the bed or chair.

Look for:

- Red areas on skin that don't go away, even after the pressure is relieved
- Cracked, blistered or broken skin
- Swelling
- Open sores, no matter what size or how deep they are
- Pain at pressure points such as the back of the head, ears, shoulders, elbows, buttocks and heels
- Should you see any of these signs, be sure to let your nurse know so **treatment can be started**.

To help prevent pressure sores:

- Keep the skin dry and clean of urine, perspiration, and other drainage
- Check for red areas or swelling
- Use lotion (applied gently) on dry, cracked, or peeling areas
- Be careful changing the patient's position to relieve pressure (how often depends on the patient's tolerance and comfort; gently lift and turn to avoid rubbing or scooting)
- Protect pressure points with heel and elbow pads

To care for pressure sores:

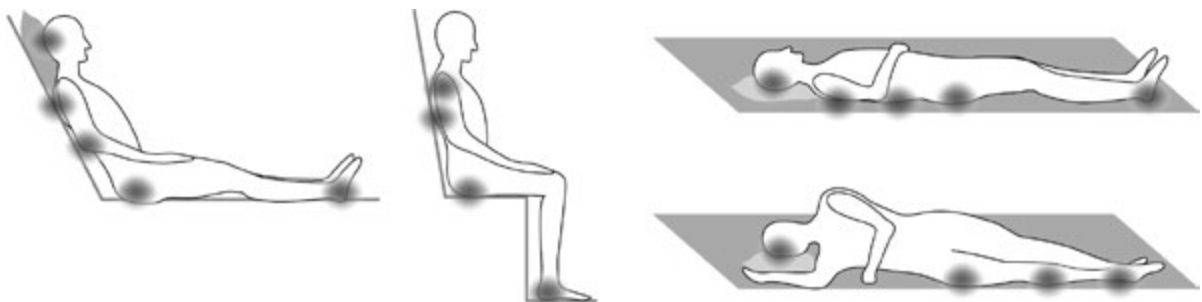
- Wash your hands before and after caring for sores
- Change patient's position as often as possible to take pressure off the sore

- Avoid rubbing, pulling or scooting (use a draw or turn sheet to reposition the patient)
- Protect the sore and the area around it, using pillows and pads
- Follow your doctor's orders for treatment of pressure sores (your nurse will show you how to carry out the orders)

Correct body alignment reduces strain on musculoskeletal structures, maintains muscle tone, and contributes to balance. Skin breakdown and pressure sores develop after there is prolonged pressure to bony areas. Buttocks, shoulders, heels, elbows and other bony prominences are at risk for developing sores. This picture shows the areas of pressure that should be observed daily for any bed-bound patient:

Bed positioning is used for prevention of pressure sores, contractures, relief of existing sores, and the patient's comfort.

Before using these repositioning tips, ask your nurse or aide to show you how to move the patient the first time. Also, for a patient with any form of paralysis, your nurse or aide will give you individual instructions for support of the affected areas. It may be necessary to give the patient pain medication prior to initiating significant changes in position, depending on the patient's condition. Talk with your nurse about whether pre-medicating the patient is advisable.



Swallowing Difficulty

As the body becomes weaker, it also becomes more difficult to do many common things, such as swallowing. “Dysphagia” is the medical term for difficulty swallowing. Choking or coughing can also occur when the person is eating or drinking. This can make it more difficult to take medications as well.

The following are suggestions for dealing with swallowing problems:

- Before giving foods or medicine, try sips of water (if coughing or choking occurs, don't panic or slap the patient on the back; instead, turn the patient onto his or her side or help him spend more time sitting up)
- Always help the patient to a sitting position in bed or in a chair before giving foods, liquids, or medications
- If the patient tends to choke, tilt the head forward during swallowing
- Thicker liquids are sometimes easier to swallow; it may help to make milkshakes or add gelatin to liquids to thicken them
- Use high-calorie, commercial supplements
- For difficulty taking multi-vitamin pills, discuss use of liquid vitamins with nurse
- The blender may be used to puree foods or try soft foods such as puddings, mashed potatoes, applesauce, or Jell-O
- Good oral care is important (sometimes dryness may cause choking)
- Some medicines can be crushed and given in soft foods to make swallowing easier (time-release medications, such as MS Contin, Oramorph, or Slow-BID **MAY NOT** be crushed). Please check with your nurse before crushing medicines; sometimes medicines come in liquid or suppository form and can be administered by a different route if swallowing is difficult.
- Frequent choking or difficulty swallowing may be associated with the disease process (your nurse can discuss this with you)

Oral Suctioning

As disease progresses, a patient may not be able to swallow correctly or to cough up the secretions in the mouth, which can make a “rattling” sound as the breath moves over the relaxed vocal cords. The secretions do not usually bother the patient, but the “rattling” sound that normally occurs as the patient breathes through them may be upsetting to the family.

When secretions such as mucus and phlegm build up in the mouth and the back of the throat, we often consider oral suctioning. Since oral suctioning can sometimes be uncomfortable for the patient, your doctor may recommend medications to help dry up the secretions. You may also elevate the patient's head a little and position him on his side so secretions can run out of the mouth naturally, by gravity.

Talk with your nurse if you are concerned about this issue. Should it be decided that suctioning is the best course of action, your nurse will demonstrate the procedure first, and when you are comfortable, have you demonstrate the procedure back to him or her.

If you, the doctor, and the nurse decide on oral suctioning, the steps are:

- When the suction machine is delivered, the nurse will give you a demonstration and teach you to use the machine
- Wash your hands before beginning, and put on disposable gloves
- Turn on the suction machine
- Place the hard plastic tip, or “Yankauer catheter,” into a small amount of water to test the suction equipment and to moisten the tip. Gently place the plastic tip into the mouth of the patient to suction the secretions
- Be aware that the farther the tip goes down into the back of the throat, the more likely the patient will gag and/or cough
- After cleaning the secretions from the mouth, clear the tubing by suctioning more water
- Empty and clean the collection container with warm soapy water at least daily, or when it is 2/3 full (keep the tonsil tip clean by placing it back in the packaging)

Swelling

Swelling is caused by a collection or build-up of fluid in the tissues. Swelling may occur anywhere in your body. Possible causes are tumor growth, liver or lymph involvement, and other medical conditions. Swelling is sometimes referred to as “edema,” “lymphedema,” or “ascites.” Ascites is swelling in the stomach area, and it may cause shortness of breath, especially when lying down. Look for swelling in the arms, legs, abdomen or any body part. Report any swelling or distress from swelling to your nurse.

To help ease swelling:

- Elevate and support the swollen body part using pillows or towels
- Apply lotion or creams to keep the skin moist
- Use warm (not hot) compresses or bath which may feel soothing
- Elastic stockings or support hose may be helpful for a swollen leg, but should be ordered by your doctor. Your nurse will show you how to use them
- Protect the swollen area from cuts or scratches to avoid infections
- Move a swollen arm or leg as much as possible
- Avoid tight clothing (such as socks or underwear) or tight jewelry (such as rings)
- Avoid sitting with feet dangling for long periods of time
- Take any medications ordered by your doctor for this problem as they are prescribed

Urinary Tract Infections

Although they are not uncommon, Urinary Tract Infections can cause significant discomfort and life-threatening complications. Various conditions contribute to the development of Urinary Tract Infections (UTIs). These include:

- Presence of an indwelling catheter
- Dehydration (fluids normally flush bacteria out of the bladder; decreased fluids allow bacteria to accumulate)
- Poor hygiene that permits bacteria to travel into the bladder

To help prevent UTIs:

- Increasing fluids, if possible
- Cranberry juice or citrus juices
- Ascorbic acid supplements*
- Good hygiene and skin care (see “Skin Care” in this guide)
- Good catheter care

Signs and Symptoms of a UTI:

- Burning sensation while urinating
- Frequent urge to urinate, but only small amounts of urine passed
- Back pain or flank pain
- Chills
- Fever
- Change in urine color and character (such as blood, mucus, and odor)

*If you are taking any over-the-counter or herbal medications, let your nurse know to include them in your list of medications.

If you suspect you have a UTI, call your nurse.

MEDICATIONS

Medication Safety

The medications that you receive for your hospice-related illness will either come by Fed-Ex from Enclara.

- **Inspect the package:** read the name and address on the outside of the package or bag to make sure that it is addressed to you. If it is not, do not open it. Call your nurse and let him or her know that there is an error.
- **Open the package** if the outside name and address are correct.
- **Read the label** on the medicine bottle to make sure the bottle is clearly labeled with your name and that the name of the medication is one that you expect.
- **Read the instructions** on the label and make sure that they are correct. This includes how often to take it.
- **Examine the Medications.** Next, open the bottle and look at the contents. If it is a medication you have been taking, do the pills look the same? You should not have two or more different kinds of pills in the same bottle. Do the pills look discolored or like they have been wet or melted? Does the number of pills seem right? Use the same care in looking at liquid medications or patches. Read labels carefully and make sure the contents look the way they should. If you have any concerns about the pills or their appearance, call your nurse.
- **Call your nurse** if there is anything you do not understand or doesn't seem right.

Changing doses or timing

The medications that you receive have been prescribed to fit your needs. They should be taken exactly as the prescription reads. Do not take extra doses or take doses too close together or too far apart. Only a physician should change a dose or the time between doses. Call your nurse if you feel your medications needs are not being met.

Other people's medications

Do not share your medication with other family members or neighbors, and do not take medications prescribed for someone else. You may have an allergy to some ingredient in the medication, or you may be taking another medication which would cause a drug interaction. If you accidentally take some medication that is not prescribed for you, please notify your nurse or your physician immediately.

Over-the-counter and herbal medications

If you are taking any over-the-counter or herbal medications, let your nurse know to include them in your list of medications. They can sometimes cause overdoses and interactions. Make sure that your physician is aware of these additional medications when he or she is prescribing a new medication for you.

Prescriptions Delivered By Mail



Enclara Pharmacia

Enclara Pharmacia is a specialized mail-order pharmacy. Their team supports your nurses and doctors who help to make your life easier and more comfortable and assure that you are receiving the most appropriate and safest medications.

Emergency Medication Packs

Upon request from your physician, Enclara Pharmacia will send you a pre-packaged box of medications. You may receive up to three boxes, depending on your medical condition. The medications in these boxes are for use in urgent situations, and are only to be used when the nurse or doctor directs you to do so.

Some of the boxes offered by Enclara Pharmacia include the Standard ComfortPak, the Cardiac ComfortPak, and the Seizure ComfortPak. Please store these boxes according to directions on the box. The medications in these kits are to manage any emergent symptoms quickly and to keep the patient as comfortable as possible.

Standard ComfortPak

- Keep out of reach of children
- Use only as directed by a nurse or physician
- Note your packaging may look different

COMMON MEDICATIONS

Prescribed for Covenant Care Patients

Anorexia Medications:

Commonly used hospice medications in this group:

- Periactin
- Prednisone
- Dexamethasone
- Megace

Common uses:

Under certain circumstances, we try to stimulate appetite in the patient who has a desire to eat, but is unable to. We do not always treat anorexia in life-limiting illness because loss of appetite is common when the body is having difficulty processing food.

Forcing food when a person has no desire to eat is seldom beneficial. It often adds to the patient's stress and discomfort.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Common side effects of medicines for anorexia include weight gain, increased appetite, easy bruising, and stomach irritation.

Anxiety Medications

Commonly used hospice medications in this group:

- Ativan (Lorazepam)
- Alprazolam (Xanax®)
- Diazepam (Valium)
- Haloperidol (Haldol)
- Phenobarbital

Common uses:

These medications are given to relieve anxiety and confusion.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will be happy to review these instructions with you.

Side effects and cautions:

Medications for anxiety may cause sleepiness, dizziness, or unsteadiness in walking. Talk with your nurse or physician if you notice problems that may relate to the use of the medication you are taking.

Blood Thinning Medications

Commonly used hospice medications in this group:

- Aspirin
- Warfarin (Coumadin)
- Enoxaparin (Lovenox)

Common uses:

These drugs are commonly used to prevent clots in people who are at risk. If the physician thinks that the patient's risk of harm from a clot is greater than the risk of bleeding from the blood thinner, then the physician may recommend taking a blood thinner.

How to use this medication:

Coumadin is a pill. It should be taken at the same time each day. Blood tests will have to be performed to adjust the dosage. It should always be taken as prescribed by your doctor, according to the instructions of your nurse. Lovenox is injected under the skin, much in the same way as insulin. You or a family member can be trained to do the injections. After a platelet count on the third day of medication, there will not be any more blood tests required.

Cautions:

Coumadin interacts with many other medications and some foods. Lovenox does not usually interact with other medications or foods. You should not take aspirin or herbal supplements if you are on any blood thinner. Aspirin is a blood thinner and can increase the risk of bleeding when it is taken by someone who is also on other blood thinners. When you are on blood thinners, you should watch for signs of bleeding. These include, bloody urine, bloody stools, black tarry stools, easy bruising, and bleeding gums.

Breathing Difficulty: Dyspnea Medications

Commonly used hospice medications in this group:

- Albuterol (Proventil, Ventolin)
- Nebulized Morphine
- Morphine Sulfate
- Diazepam (Valium)
- Alprazolam (Xanax)
- Oxygen
- Lorazepam (Ativan)

Common uses:

These medications are given to relieve dyspnea, or shortness of breath. Though shortness of breath is a common occurrence in life-limiting illness, we recognize that it is very frightening for the patient and family whenever it occurs. If you call your care team immediately, we will visit as quickly as possible to help get this symptom under control so that the patient is more comfortable.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects and options:

Albuterol may cause nervousness or agitation. Morphine, Diazepam, and Alprazolam may cause sleepiness or dizziness. Oxygen may cause dryness of the nose or mouth. Talk with your nurse or your physician if you notice problems that may relate to the use of the medication you are taking.

Cough Medications

Commonly used hospice medications in this group:

- Benzonatate (Tessalon perles)
- Dextromethorphan (Delsym)
- Guaifenesin
- Guaifenesin/Dextromethorphan

Common uses:

These medications are often prescribed to treat coughs. It should be noted that the narcotic component of pain medications you may already be receiving is also a cough suppressant.

Depression Medications

Commonly used hospice medications in this group:

- Methylphenidate (Ritalin)
- Sertraline (Zoloft)
- Paroxetine (Paxil®)
- Celexa
- Prozac

Common uses:

This medication is often prescribed for depression, which occurs frequently in patients who have a life-limiting illness.

Sadness is a normal stage of grief and loss. The problem occurs because it is easy to get “stuck”

in depression. Talk with your doctor or nurse if you feel that you or your loved one is “stuck” with an overall depressed mood that he or she cannot shake off.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will be happy to review these instructions with you.

Side effects:

Possible side effects include nervousness, inability to sleep, drowsiness, dizziness, headache, nausea, and diarrhea.

Diabetes, Blood Sugar Medications

Common Uses:

Insulin is used to reduce the level of blood sugar when it is too high. High blood sugar is also called “diabetes.” Some hospice patients develop diabetes due to their illness or the treatment of their illness, even though they were not diabetic before. People who are on insulin need to have their blood sugar checked frequently to adjust the dosage.

How to Use This Medication:

Insulin is injected under the skin. You or a family member can be trained to do this safely. The blood sugar is checked by sticking a finger to obtain a sample and putting it in a glucometer which is kept in the home. Your nurse can train you or a family member with this procedure.

Cautions:

If the blood sugar is permitted to get too high, it causes thirst and dehydration. If the blood sugar is permitted to fall too low, it causes sweating and confusion. If any of these symptoms are noticed, the blood sugar should be checked and a call made to your nurse. If the blood sugar level is not corrected it can result in coma or seizures.

Side Effects:

If insulin is used correctly, there are rarely any side effects. Sometimes there may be bruising at the site of the injection.

Diarrhea and Gas Medications

Commonly used hospice medications in this group:

- Loperamide (Imodium)
- Cholestyramine (Questran)
- Simethicone (Mylanta-Gas, Gas-X)
- Lomotil -Diphenoxylate Hcl/
Atropine Sulfate
- Bismuth Subsalicylate (Pepto Bismol)

Common uses:

These medications are prescribed to treat diarrhea and uncomfortable intestinal gas.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Constipation is a possibility. Discuss any concerns with your nurse.

Infections: Antibiotic Medications

Commonly used hospice medications in this group:

- Cephalexin (Keflex)
- Amoxicillin (Trimox)
- Sulfamethoxazole/Trimethoprim
(Septra/Bactrim)

Common uses:

These medications are given to fight bacterial infections, such as urinary tract infections. Hospice patients commonly use the oral form of antibiotics. Intravenous antibiotics are seldom used in this setting.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will be happy to review these instructions with you. "Daily" means one dose each day. "Three times a day" means a dose every 8 hours, and "four times a day" means a dose every 6 hours.

Side effects and cautions:

These medications may cause diarrhea with cramping, nausea, rashes, or yeast infections. Talk with your nurse if you notice problems that may relate to the use of the medication you are taking.

Mouth Ulcer Medications

Commonly used hospice medications in this group:

- Magic Mouthwash
- Viscous Lidocaine (Xylocaine 2%)
- Nystatin suspension

Common uses:

These medications are often prescribed to treat mouth ulcers, which are a common complication of end-stage illness.

How to use this medication:

This medication may be taken with food. It should be taken exactly as prescribed by your

doctor. Your nurse will review these instructions with you. "Daily" means one dose each day. "Three times a day" means a dose every 8 hours, and "four times a day" means a dose every 6 hours. It is usually administered by the method of "swish and swallow" or "swish and spit," which means swishing the medication around in the mouth for several seconds and then either swallowing it or spitting it out.

Side effects:

Mouth numbness is a common side effect, but it is not a cause for concern.

Muscle Spasm Medications

Commonly used hospice medications in this group:

- Diazepam (Valium)
- Baclofen (Lioresal)
- Cyclobenzaprine (Flexeril)
- Carisoprodol (Soma)

Common uses:

These medications are prescribed to treat muscle spasms.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Common side effects include sleepiness and dizziness.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Possible side effects include dizziness, headache, and rash.

Nausea and Gastrointestinal Medications

Commonly used hospice medications in this group:

- Promethazine (Phenergan)
- Prochlorperazine (Compazine)
- Famotidine (Pepcid)
- Ranitidine (Zantac)
- Metoclopramide (Reglan)
- Maalox and Tums
- Haloperidol (Haldol)
- Zofran (Ondansetron)
- Milk of Magnesia

Common uses:

These medications are often prescribed to relieve constipation, which is a common side effect of many of the medications used to treat pain in hospice care. We try to start the patient on a regimen to prevent constipation at the

same time that we start treatment with pain medication, since it is much easier and more comfortable to prevent constipation than to take care of it once it has developed.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you. Over-the-counter medications should be taken according to instructions on the package, unless your physician directs you otherwise.

Side effects:

Side effects of medicines for constipation include cramping and diarrhea.

Nerve Pain Medications

Commonly used hospice medications in this group:

- Amitriptyline (Elavil®)
- Gabapentin (Neurontin)
- Desipramine (Norpramin®)

Common uses:

These medications are given to relieve nerve pain. Elavil and Norpramin® are also used for depression. Neurontin is also used for seizures.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects and cautions:

These medications may cause sleepiness, dizziness, dry mouth, increased appetite, or urinary retention. Talk with your nurse or physician if you notice problems that may relate to the use of the medication you are taking.

Oral Secretions Medications

Commonly used hospice medications in this group:

- Hyoscyamine (Levsin)
- Glycopyrrolate (Robinul)
- Atropine Ophthalmic Solution
- Scopolamine (Transderm Scop)

Common uses:

These medications are often prescribed to treat excess secretions, which frequently occur when the patient is dying. The secretions often cause a gurgling in the throat because the patient is not able to swallow or clear them as he or she usually does. It is not necessary to treat this condition, because all indications are that it does not cause discomfort for the patient. The family may be distressed by

the sound, however, and may prefer to take measures that decrease the secretions in some way. It is possible, but rarely helpful, to use a suction machine for this purpose. It may be helpful to turn the patient on his or her side so that the secretions can drain.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Possible side effects include dry mouth and eyes, constipation, blurred vision, and sleepiness.

Pain Medications

Narcotics

Commonly used hospice medications in this group:

- Hydrocodone (Lortab, Vicodin, Norco)
- Methadone (Dolophine®)
- Morphine or Time Release Morphine (MS Contin, Oramorph)
- Oxycodone
- Hydromorphone (Dilaudid)

Common uses:

These medications are used to control pain. They are prescribed for specific times of dosing to prevent recurrence (or “breakthrough”) pain.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you. It has been prescribed for specific time intervals and should be given as prescribed to prevent breakthrough pain.

Side effects:

These medications may cause itching, and may cause the patient to become sleepy or nauseated. These side effects will usually disappear after a few days. Constipation is an expected side effect and does not go away as long as you are on pain medication. A person who is taking pain medication regularly should also be on a regimen that will prevent constipation.

Morphine Liquid Concentrate

Commonly used hospice medications in this group:

Roxanol or MSIR are a concentrated form of immediate-release liquid Morphine Sulfate.

Common uses:

Morphine Liquid Concentrate is usually given when a patient is having a hard time swallowing pills. It is absorbed in the mouth and the large blood vessels under the tongue. It doesn’t need to be swallowed in order to be effective.

How to use this medication:

Give on a regular schedule even if the patient is unable to swallow. Place the medication under the tongue, between the lips and gum, or in the cheek area.

Side effects and cautions:

These medications may cause the patient to become sleepy. This side effect will usually disappear after a few days. Nausea and vomiting are occasional side effects which will also disappear after a few days. Constipation does not disappear. When you are taking pain medications, it is a good idea to use stool softeners and a bowel regimen to prevent constipation. Your nurse will discuss this with you.

Long-Acting Pain Patch

Many patients will eventually be unable to take their medications by mouth. The use of a patch may be the a good method for managing the patient's pain at this time. If the patient is extremely thin, and/or has poor circulation, it may not be the best route.

The patch contains a medication called Fentanyl (Duragesic), which is a strong pain reliever. Medication is absorbed through the skin, then into the bloodstream. Initially it may take a few days to control pain, so another medication may also be needed for breakthrough pain.

How to use this medication:

Remove backing and place patch on clean, dry skin which is not irritated or broken. Place on flat part of the upper body, such as the chest or back. Fold sticky sides together when removing old patch. Flush down toilet. Wash your hands. DO NOT place on skin which has recently been exposed to radiation. DO NOT shave the hair where the patch is to be placed – but hair can be clipped. DO NOT leave patches in reach of children. DO NOT CUT PATCHES. Remember to leave the patch on as ordered by your doctor. Contact your nurse with any questions about the patch.

Rectal Medication Administration

As illness progresses, it is not uncommon for a patient to lose the ability to take medications by mouth. Some medicine for pain and other symptom control may need to be given rectally, if the medication is designed to be absorbed that way (suppositories). Your nurse will review these procedures with you until you are comfortable giving medications rectally. Some suppositories may require refrigeration. Check the instructions on the container upon receipt.

Follow these steps:

- Wash your hands.
- Put on gloves.
- If the medicine is a suppository, remove the foil wrapper.
- A pill or capsule can be put directly into the rectum, or the medicine may first be put into a gelatin capsule and then put into the rectum (gelatin capsules are available at a drug store).
- Put a large dab of water-soluble lubricant on the suppository, capsule, or pill.
- If possible, have the patient lie on the left side with knees pulled to the chest. Tell the patient to take a few deep breaths and relax as you gently insert the medicine into the rectal opening with your gloved hand.
- Push the medicine in as far as it will go and place it against the rectal wall. If the rectum is full of stool, the patient will need to have a bowel movement before the medicine is placed in the rectum.
- The patient may feel the need to have a bowel movement after the medicine is put in the rectum. Try to get the patient to hold the medicine in for at least 20 minutes so that it will be taken in by the body before moving his or her bowels.
- Cover the patient and make him or her comfortable.
- Take off the gloves and wash your hands.

Seizure Medications

Commonly used hospice medications in this group:

- Diazepam (Valium)
- Phenytoin (Dilantin)
- Levetiracetam (Keppra)
- Valproic Acid (Depakote)
- Phenobarbital

Common uses:

This medication is often prescribed for the prevention and treatment of seizures, which sometimes occur as a complication of severe life-limiting illnesses.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor, according to the instructions of your nurse.

Side effects:

Common side effects include dizziness and sleepiness. Please talk with your nurse if you experience symptoms that you think may be related to the use of this medication.

Sleeping & Sedative Medications

Commonly used hospice medications in this group:

- Temazepam (Restoril)
- Diphenhydramine (Benadryl)
- Trazodone (Desyrel)
- Quetiapine (Seroquel)

Common uses:

These medications are used to relieve anxiety, problems falling asleep, or other reasons given by your doctor.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you. Tell your nurse if you have problems swallowing this medicine. There may be a liquid form that can be substituted. DO NOT STOP TAKING THIS MEDICINE WITHOUT INSTRUCTIONS FROM YOUR DOCTOR OR NURSE.

Side effects:

If you notice any of the following problems, please talk to your nurse about them: Drowsiness or unusual tiredness, difficulty concentrating, dizziness or lightheadedness. If you notice any of the following problems, please contact your nurse immediately: Difficulty staying awake, confusion, unsteadiness, problems walking, urinary retention, unusual agitation, anger, or behavior changes.

Precautions:

Do not double up on doses. If you miss a dose and you remember within a few hours of the due time, take it right away. If it is almost time for the next dose, skip the missed dose and take the regular dose as scheduled. Do NOT suddenly stop taking this medication. Get up slowly to avoid lightheadedness. Do NOT use alcohol or other medications while taking this medicine without the advice of your nurse or doctor.

Swelling: Diuretic Medications

Commonly used hospice medications in this group:

- Hydrochlorothiazide (HCTZ)
- Furosemide (Lasix)
- Spironolactone (Aldactone)

Common uses:

This medication is often prescribed to remove water and salt from your body by increasing urine flow. It may also help to lower blood pressure.

How to use this medication:

This medicine should be taken exactly as prescribed by your doctor. Your nurse will review these instructions with you.

Side effects:

Muscle cramps, dizziness, rash or hives, and tiredness.

END-OF-LIFE CARE

We are all born, and we all die. It is part of nature. There is a series of final changes that helps prepare the way. Many recent advances in medical technology are very helpful in situations where the cause of death is sudden and reversible, like choking or injury in an automobile accident. They may not be so appropriate when someone has a terminal illness, and the cause of death cannot be reversed. Although the technological interventions may prolong life briefly, they cannot prevent the inevitable, and they often can cause additional pain and suffering.

Decisions about what interventions to use should be discussed with the patient, the family, and the health care decision maker. Whenever possible, they should also be written down in an "Advance Directive" or "Living Will." Covenant Care team members are available to provide you with information or resources to assist you in making these decisions or completing these documents.

As death approaches, the body slowly and naturally begins to shut down systems. Many patients stop eating at the end of life because the digestive system is one of the first body systems to shut down, and eating becomes uncomfortable and undesirable.

As the body's need for food decreases, the patient no longer feels hungry. Although the body no longer needs physical food, spiritual and psychological "food" such as love, prayer, meditation, support, counseling, presence and peace, is often very helpful.

If we continue to push physical food or fluids, the circulatory system (heart and lungs) can become over-stressed. It is trying to shut down, and the additional food and fluids create an increased burden the body cannot handle. Because it cannot keep up with the fluids being pumped into the veins, the fluid has nowhere to go but into the lungs. This can cause difficulty breathing and discomfort and stress for the dying patient. Since many people fear that the patient will suffer if dehydration occurs, we hope that you will find the following information useful. It is a list of "pros" and "cons" the patient will experience when we stop aggressive treatments and allow the body to die naturally.

Cardiopulmonary Resuscitation (CPR)

Your nurse or social worker will talk with you about signing a document called a "Do Not Resuscitate" ("DNR") order in Florida or a "Do Not Attempt Resuscitation" ("DNAR") order in Alabama. We hope that you will discuss these issues with your family and with us so that your end-of-life care involves the interventions you would choose to have.

Once a DNR/DNAR is completed, please keep it in a safe but easily accessible location in case 911 is called at any time. Notify family and your nurse where the DNR/DNAR is located.

Dehydration

EFFECTS OF DEHYDRATION	BENEFITS	POSSIBLE NEGATIVE EFFECTS
Decreased urine output	Less need for bedpan, urinal, commode, catheter. Less incontinence, increased comfort.	Can cause increased potential for UTI and abdominal discomfort
Decreased lung (pulmonary) secretions	Reduced coughing and congestions	Continued cough reflex
Decreased throat (pharyngeal) secretions	Relief from choking & drowning sensations, less need for suctioning	Continued fear that choking may occur
Decreased volume of body fluids	Decreased swelling & edema around lungs, easier to breathe	
Reduced swelling around tumor	Relief from pain & pressure around tumor mass, less skin breakdown	
Increased concentration of electrolytes	Natural anesthetic agent for central nervous system. Increases drowsiness, decreases awareness of suffering, disorientation	Increased neuromuscular irritability, cardiac arrhythmia, twitching, restlessness, nausea
Decreased moisture in mucous membranes		Discomfort from dry mouth, cracked lips

Signs and symptoms of approaching death

Members of the Covenant Care team will be alert for the signs and symptoms that occur as death becomes “imminent,” or near, and will assist you in becoming aware of these changes as they present themselves. When these changes begin to happen, the most appropriate response is to make the patient as comfortable as possible, and surround him or her with support and peace. It is important to keep in mind that the changes are not medical emergencies, but a natural part of the process leading into the final phase of life. With our help you can be confident in your ability to bring comfort to your loved one.

Physical changes involve the cessation of bodily functions. Mental, psychological, and spiritual changes involve resolution and completion. These processes are predictable, but the ways each person experiences them are very individual. The following are signs and symptoms of entering the final stage of life, with suggested appropriate responses to them:

Physical Signs and Symptoms

Coolness:

The person’s hands, arms, feet, and legs may be cooler to touch. Skin color may also change: the underside of the body may be darker, with different shades of blue or purple. This is called mottling. This is an expected sign that circulation of blood to these areas is decreasing and is being reserved for the more vital organs. Keep the person warm with a blanket. Do not use an electric blanket or heating pad.

Sleeping:

The person may sleep more, appear to be unresponsive, and be difficult to wake up. This normal change is due to changes in metabolism. Sit with your loved one, hold his/her hand, but do not shake the person or speak loudly. Spend time with him/her during the periods when he or she seems most alert and awake. Do not talk about the patient in his/her presence. Speak to the person directly, as you normally would. Never assume that the person does not hear you, as hearing seems to be the last of the five senses to be lost.

Disorientation:

Your loved one may be confused about the time, place, and identity of the people surrounding him/her, including close and familiar people. This is also due in part to the metabolic changes. Identify yourself by name before you speak. Speak clearly, softly, and truthfully when you need to communicate something important for the patient’s comfort, such as, “it’s time for your medication.” Explain the reason, such as, “so you won’t begin to hurt.” Continue to honor choices the person made at

earlier points and be careful not to manipulate the patient to meet your needs.

Incontinence:

Your loved one may lose control of urine and/or bowel functions as the muscles in that area begin to relax. Discuss with your nurse what can be done to protect the bed and keep your loved one clean and comfortable.

Congestion:

The patient may have gurgling sounds coming from his/her chest. These sounds may become very loud. This normal change is due to the decrease of fluid intake and relaxation of muscles. Suctioning usually INCREASES these secretions and can cause sharp discomfort. Gently turn the patient to one side, prop with a pillow to the back, and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate severe respiratory distress or new pain, though it may be distressing to you.

Restlessness:

Your loved one may make restless and repetitive actions, such as pulling at the bed linen or clothing. This often happens and is due partly to the decreased oxygen to the brain and partly to metabolic changes. Do not interfere or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage the forehead, read to the person, make the lights softer, or play some soothing music. Give assurance that you are there and will remain there.

Fluid and Food Decrease:

The person may have a decrease in appetite and thirst, wanting little or no food or fluids. This is natural. Do not try to force food or drink, or to use guilt to manipulate the person into eating or drinking. Eating only causes more discomfort because the body is naturally trying to conserve energy and is no longer able to process food. Chips of ice or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask your nurse for guidance). Moistened swabs or toothettes may keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

Urine Decrease:

The person's urine output normally decreases and may become darker. This is due to the decreased fluid intake, as well as a decrease in circulation through the kidneys. Consult with your nurse to determine whether there may be a need to place a catheter in the bladder, or whether this would increase discomfort.

Breathing Pattern Change:

Your loved one's breathing pattern may change to a different pace. A characteristic pattern consists of breathing irregularly, with rapid, shallow breaths and with periods of no breathing for 5 to 30 seconds, and sometimes as long as a minute. Different patterns are very common and indicate

a decrease in circulation in the internal organs. Elevating the head and/or turning the person onto his/her side may bring comfort. It may also be helpful to hold his/her hand and speak gently.

Fever:

It is not unusual for patients in the end stages of their illness to run a fever. There are several different things that can cause this, including infection, dehydration, or the patient's disease. If a person is experiencing other new symptoms, call your nurse. These might include:

- Lung congestion or productive cough with yellow sputum
- Sore throat
- A wound or sore that is draining pus or has a bad odor
- Burning or frequent urination or urine with mucus in it

Soak a washcloth in cool water, wring it out, and place it on the forehead and/or under each arm. (Do not put under arms if you think this causes discomfort).

Do not feel that you must check the person's temperature daily or more frequently. Usually you can tell if the person has a fever by flushed face or complaints of being hot or chilled. Then you may check the temperature under the tongue with the mouth closed for 3 minutes or under the arm for 5 minutes, if this is easier.

Non-Physical Signs and Symptoms

Withdrawal:

The person may seem unresponsive, withdrawn, or in a coma-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of "letting go."

Vision-Like Experiences:

Your loved one may speak or claim to have spoken to persons who have already died, or may see places not visible to you. This does not mean she/he is hallucinating or having a drug reaction. The person may be beginning to detach from this life and is preparing for the transition. Do not explain away, belittle, or argue about what the person claims to have seen or heard. It is real to your loved one, even if you cannot see or hear it. These experiences are common and are part of "nearing-death awareness." If they frighten your loved one, provide reassurance and emotional support.

Restlessness:

The patient may perform repetitive and restless tasks. At times, this indicates that something is still unresolved or may be disturbing him/her. Your care team may be able to assist you in identifying what is happening and finding ways to help. Other actions which may be helpful in calming your loved one are to recall a favorite place or a favorite experience, to read something comforting, to play music, and to give assurance that you are and will remain there.

Decreased Socialization:

Your loved one may only want to be with a very few people or only one person. This is a sign of preparation for release and a statement about the people from whom the support is most needed. If you are not part of this “inner circle” at the end, it does not mean that you are not loved or are not important. It means that you have already fulfilled your task with him/her, and it is time for you to say goodbye. If you are part of this “inner circle,” the person continues to need your support and reassurance.

Saying Goodbye:

When your loved one is ready to die and you are able to let go, then it is time to say goodbye. Saying goodbye is your final gift of love, because it helps to close the relationship and make final release possible. It may be helpful to be in bed with him/her, to hold him/her, or to take his/her hand and say anything you need to say. This may be as simple as saying, “I love you.” It may include remembering a favorite experience you shared. It may also include saying, “Thank you for . . .” The essentials of final leave-taking include, “Forgive me,” “I forgive you,” “Thank you,” “I love you,” and “Goodbye.” Tears are a normal and natural part of saying goodbye, and do not have to be hidden from your loved one or apologized for. Tears express love and help you let go.

Care at the Time of Death

While dying can bring feelings of sadness and a lot of anxiety, there are some very simple things that you can do to make your loved one more comfortable. Sometimes just creating a peaceful atmosphere can help make a dying person feel calm and safe. Our goal is to let you know what to expect when your loved one is nearing death and to feel confident that their needs will be met with care and compassion.

It is important to talk with your loved one about his or her end-of-life goals and wishes. Does the patient want particular people (or pets) to be present at the time of death? Where does the patient want to die? These are difficult questions, but discussing them when the patient is able to help make decisions eases the strain when the time comes to “let go” and allows the patient to die with dignity on his or her own terms. It is also important not to be embarrassed or apologetic about carrying through with these wishes, even if a friend or family member might think some part of the choice is strange.

While the patient or family may no longer hope for a cure, there is still much hope in this situation that can seem “hopeless.” The new hope may be to see another day, to be free of pain, to see a grandchild, or to say goodbye to a child or other relative who lives at a distance. You can help your loved one by identifying what kinds of goals he or she has, and our staff will work with you to achieve them, if possible.

The environment can be made much less “medical” and more home-like. Sometimes putting out familiar photographs, rosary beads, pillows, or favorite books

are helpful things to do. Can the bed be repositioned to allow the patient to look out a window? Is the patient isolated in a bedroom? It is possible to put the bed in a living area to make the patient feel less lonely?

If it is available, natural light is always better than harsh lighting. You can ask the patient whether he or she wants the lights on or off. Give the patient choices whenever possible, but understand that at the end of life, the patient may not be able to tell you what he or she needs or wants. Pay attention to the noise level in the room. If the patient isn't used to having the television turned on all day and night, for example, try to keep on a familiar schedule. It helps to keep the natural day/night, sleep/awake cycle whenever you can.

Make sure there are comfortable chairs near the patient for visitors he or she wants to see. Don't be afraid to ask visitors to keep their visits short if the patient tires easily. You can always post a sign on

the door asking visitors to return at another time if the patient is sleeping. If the family is keeping a vigil, it is important to notice the patient's response to the noise level or to limit the number of people so that the environment is not too stimulating or distracting.

Often, patients become withdrawn and sleepy during their final days. Try not to take this personally; it is nature's way of helping the person "let go." Some patients have visions. It is not uncommon for patients to have conversations with relatives who have died years ago. Pay attention even to confusing things your loved ones may say. Sometimes, they're letting you know that they are preparing for a journey. They may even ask for money, or car keys, or a map, or seem to be looking for someone. These are all ways in which patients let those of us who pay attention know that they are leaving this life. Not every patient has these experiences, but they are common at the end of life.

When your loved one dies, CALL COVENANT CARE first! DO NOT CALL "911."

A nurse will come to where the patient is and do an assessment. If all breathing and heartbeat sounds are gone, the nurse or physician will "pronounce" the death of the patient. This is a medical term that means the nurse will tell you that the patient has officially died. The death event can be frightening, but much less so if you are prepared. Don't be afraid to ask your nurse about what to expect as death approaches.

You will have some choices to make when your loved one dies. It will be important to know which funeral home you want to use. Will you want to watch when the funeral director comes to remove the body, or will you want to be in another room? Will you want your loved one's face covered or uncovered when the body is removed? While these are difficult to think about, planning in advance helps to reduce anxiety once your loved one dies. Some families want to spend time with the body in order to say their good-byes. Some families don't want to stay with the patient at all. Either way is okay. There is no "right" way, and there is no "wrong" way. Do what you need to do.

Covenant Care offers bereavement services, and someone from Covenant Care will be calling you within the next several weeks to check on you. If you need help before Bereavement Services contacts you, just call Covenant Care and let us know. We want to offer you all the support we can during this difficult time.

Honoring Your Loved One

Funeral Arrangements

Your social worker and other members of your Covenant Care team will ask about your funeral arrangements and suggest that it might be beneficial to make arrangements in advance. Funeral arrangements can be complicated, overwhelming, and expensive. By making plans with the funeral home in advance, or “prearranging,” one can compare prices, make informed, unhurried decisions, ensure funeral wishes are met, and relieve family and friends from having to make rash decisions in the midst of grief.

You can inquire about funeral home prices and services by phone or in person. Many local funeral homes have representatives that will visit your home and explain their options, services, and prices, as well as give you a written price list of available services and costs.

If you or your family feels you are unable to pay for final arrangements, please discuss this with your social worker. The social worker may be able to offer suggestions or address any additional questions, concerns, or needs. Please let us know of any specific cultural or religious preferences so that we can address your needs accordingly.

Obituaries

An obituary is most interesting and meaningful if it is individualized to include your accomplishments, people special to you, and any other information you feel is important. If it is not written in advance, many things get left out because the family is rushed, unable to find dates and details, and still under emotional distress due to the loss. Even if the obituary is not completely written out, it helps to gather the data to be included.

Newspapers may have a limit to the content of the obituary. There is also a charge for running it in the paper. The newspaper or funeral home can provide you with information on cost. Covenant Care recognizes that you may not want to write an obituary in advance, and we also respect your sentiments if this is the case. Inform your care team of your wishes and needs so they can best help you.

CARE FOR THE CAREGIVER

Caregiving can be very rewarding, but it can also be emotionally and physically draining. In order to provide the care your loved one needs, you have to care for yourself. This is not an act of selfishness, but helps you better care for your loved one. It is important to take time for yourself without guilt.

Consider this: when you are on an airplane waiting for takeoff, the flight attendant talks to you about what to do in an emergency. The attendant tells you that if you have small children, you should put the oxygen mask on yourself before placing one on your children. This way you can take care of your children. This same concept should be applied to caregiving. You cannot care for your loved one if you do not take care of yourself.

Helpful hints for the caregiver:

- **Set limits/Say “NO”:** Decide your limits ahead of time if possible and stick to them. When people ask you to do something that will add more stress and responsibility for you, say no.
- **Accept Help:** When people offer to help, give them something specific to do. Even if you feel you do not need help at that time, take advantage of the offer, because things may be difficult tomorrow, and feeling rested will be an advantage. Pace yourself. Use services available from Covenant Care, such as a home health aide and a volunteer.
- **Get Enough Rest:** Sleep when your loved one is sleeping. Take time to just lie down in a quiet place and rest your mind and body. This can also be done during the aide’s visit.
- **Focus on Good Nutrition:** Eating right can give you energy and help your mind work better. Stay away from caffeine, chocolate, and unnatural energy boosters. Start your day with breakfast. Eat vegetables, grains, fruit, and lean meat.
- **Utilize Support:** Spend time with those who listen, validate and support you, including church members, family, friends, etc. Share your feelings and experiences. You may also want to join a caregiver’s support group. Let others know what you need.
- **Acknowledge Your Feelings:** Caregivers may experience many different feelings, including anger, guilt, fear, helplessness, sadness, etc. Express these feelings in constructive ways. Share them with your care team or a confidant. Keep a journal.
- **Validate Yourself:** Use self-talk to stay positive. Remember you are only one person, and you are doing everything you can. It is normal to get angry or frustrated with your loved one sometimes. Forgive yourself. You are just reacting to the stress. Being present and being reassuring to your loved one is often more important than anything else.
- **Involve Others:** Allow other family members or friends to participate in care. Set up a schedule. Rest or do something you enjoy on your time off.
- **Let Things Go:** You do not have to have the cleanest house or the nicest lawn on the block. Remember you are only one person, and can only do one thing at a time.
- **Laugh or Cry:** Laughter relieves stress. It is also good medicine for the patient. Tears help cleanse our bodies by removing stress-related chemicals. Suppressing tears may increase our susceptibility to illness.
- **Utilize Respite:** Spend time away from caregiving as you are able. During this time away, relax and find ways to relieve stress (exercise, journaling, breathing exercises, meditation). Volunteers are available through Covenant Care to assist with respite care.

Understanding Grief

When someone in a family or social group has a life-limiting illness, everyone who cares about that person may be strongly affected. Elizabeth Kubler-Ross was the first to describe the range of emotional reactions that typically occurs. She outlined five distinct stages of terminal illness, which include denial, anger, bargaining, depression, and acceptance. Kubler-Ross noted that this same group of reactions occurs when someone is anticipating or reacting to an impending loss, including the loss of a family member.

Though this range of responses is present in most people, it is important to recognize that each individual is different and may experience the stages in a different order. Some people bounce back and forth, or even experience a combination of feelings and emotional reactions at one time. This is often called the “emotional roller coaster.”

Denial: It is common to feel that “this is not happening to me/us”. The mind often shields us from fully grasping a new reality until we have the strength to deal with it and protects us at times when our defenses are low. If you or your loved one is diagnosed with a life-limiting illness or referred to hospice, give yourself time to adjust to the situation and accept things. It is often hard for a family to complete necessary business (advance directives or funeral arrangements) when they or the sick person are in denial. If you are having a hard time accepting the reality of the situation, use a “just in case” approach to think about the necessary arrangements. Do not try to force yourself to change the way you are thinking about things, but follow through with the planning “just in case” things do not go as you hope they will. Patience and willingness to talk are important. Often one or two family members are in denial and feel more should be done to help the patient improve. Try to get them to focus on what the patient wants, rather than trying to break down the denial another person may be using to cope.

Anger: Anger is a normal response that can occur at different times throughout the illness. Questions of “why?” and envy of those who are well are common reactions. Anger can be directed at family, friends, God or a higher power. It is important to express this anger constructively.

Bargaining: Bargaining occurs when the patient or family is closer to acceptance, but “bargains” for a longer time or for freedom from pain or decline. The person makes an agreement like, “I know I am dying, but I want to live long enough to see my granddaughter get married or my son graduate from high school.” It is normal to do this, and good things often come from it. Recognize there is some flexibility about the timing of death, and listen empathetically to the patient who expresses sentiments like this. Share with one another and your care team. Try to make wishes and bargains that will benefit everyone.

Depression: Depression can be a normal reaction to dealing with a life-limiting illness for both the patient and family or friends. It is normal to begin to grieve and mourn losses you are experiencing and those you are anticipating. Share your feelings with someone, such as a trusted friend or your social worker. Your sorrow needs to be expressed. Recognize the signs of depression and inform your social worker or doctor so that they can appropriately intervene. Always inform your care team or doctor if you have thoughts of harming yourself.

Acceptance: This occurs when the diagnosis and prognosis are accepted and understood. Though some people never achieve complete acceptance, this stage gives those who do the opportunity to communicate goodbyes and achieve closure with one another. It also provides other chances for growth and self-actualization.

Other Symptoms of Grief:

Fear or anxiety: It is important for both the patient and the family to discuss their fears. Voicing fears helps lessen them, and naming fears will help your care team respond appropriately. There are many common fears that both patients and their families may have. These include fear of: pain, dying itself, the afterlife, the disease process, being a burden, losing control, being dependent on others, leaving loved ones, providing care, and the unknown. All members of your care team can answer questions about the feelings listed above and provide support to help ease them.

Guilt: Forgive yourself for your mistakes and focus on your successes. It is also good to be conscious of other thoughts that are reassuring. For example, remember that you are only one person and can only do one thing at a time. Keep in mind that people do the best they know how to do at any point. Talk about your feelings with your care team.

Helplessness: Rather than letting yourself get pulled into thinking about the things you can't do, focus on what you can do. The things that you can do include being present, listening, sharing memories and stories of good times, and communicating your love, sorrow, regrets or goodbyes.

Other common feelings include: shame, shock, withdrawal, desire to remember the past, blame, sadness, loss of control, loneliness, confusion, and frustration. **The important thing to know is that these feelings are normal and need to be expressed.**

Reactions to Grief and Anticipatory Grief

The first response to the death or expected death of someone you love is usually shock and denial. This can last for days or weeks, and helps protect you from being overwhelmed by your loss or impending loss. Over time, you may also respond in a number of other ways that involve the total person, since grief and anticipatory grief reactions frequently appear as emotional, physical, mental, and spiritual signs of discomfort and distress.

Emotional reactions may include:

Crying, often unexpectedly
 Anger
 Sadness
 Hopelessness
 Panic or anxiety attacks
 Helplessness
 Feeling passive
 Withdrawal
 Emptiness
 Guilt
 Despair
 Loneliness
 Bitterness
 Thoughts of not wanting to live

Physical reactions may include:

Numbness
 Difficulty in breathing
 Nausea
 Diarrhea/Constipation
 Shortness of breath
 Exhaustion
 Headaches
 Blurred vision
 Dizziness
 Pain around heart ("Broken Heart")
 Hyperactivity

Mental Reactions:

- Confusion
- Lack of concentration
- Dreams, thoughts of your loved one
- A sense of unreality sometimes with memory loss
- Fears that you are going insane
- Regrets and thoughts of “if only”
- Feelings of losing control of your life
- Inability to think clearly

Covenant Care recognizes that dealing with grief and anticipatory grief may be difficult. We are here to help you during this time and want to support you in any way possible. Please contact your social worker or another care team member for more information

Spiritual Reactions:

Personal faith is frequently a major source of comfort during bereavement. For some, however, maintaining faith may be difficult during the period of loss. Feelings of anger and the question, “Why?” are common. Either reaction may occur, and both are consistent with later spiritual growth. The following suggestions might be helpful as you make your way through the experience of grieving:

- Try to be patient and gentle with yourself; remember that trust and patience are essential as you begin to define your new course in life.
- There is no “right way” to grieve — your way is the right way for you.
- Don’t judge yourself by someone else’s grief experience or someone else’s suggestions about what would be good for you; your grief is your own.
- You cannot bring your loved one back, but your life can become more meaningful because that person loved you, especially if you take time to make the memory a part of you.
- Try to accept the support and caring that others offer.
- Seeking information about the grieving process through books, conversations with others, support groups, or workshops often makes it easier to understand and accept the changes and reactions you are experiencing.
- Talking about your feelings or writing about them in a journal are good ways to move through the process of grieving or mourning your loss.
- Creative activities such as painting, reading or writing poetry, or examining dreams can also be helpful.
- Take special care of yourself physically by eating well (even though you may not feel like it), exercising regularly (this helps increase your energy), and getting enough rest.
- It is wise to visit your family physician in the first few months after the loss, especially if you are having physical symptoms that might be helped by medication or by receiving support and understanding from a healthcare professional.
- Contact with people who have had a similar experience can give you hope (many support groups are available through Covenant Care or other community resources).
- Look for new areas of interest and involvement.
- Your Covenant Care spiritual coordinator and other members of your interdisciplinary team can be enormously helpful in talking with you and identifying resources to meet your particular needs.

Children's Reactions to Death and Dying

Children's understanding and reactions to death must be examined according to their age and developmental level, personality traits, and their previous experiences with death. However, it is also important to recognize that, like adults, children are unique individuals who sometimes cope with the events in their lives in unpredictable ways. Thus, the following information can be used as a guideline for characteristics observed in most, but not all, grieving children.

First, we will examine the concept of death as it is understood by children according to their age and developmental level. Researchers who study children have documented that even infants can be affected by the death of a close family member, particularly a custodial parent with whom they have formed an attachment. Infants are very sensitive to changes in their environments and can sense when a new person enters or when an attachment figure is not present. By the same token, an infant living in an environment where family members are experiencing and expressing grief may pick up on the emotional energy that is present, causing the infant to exhibit such behaviors as more agitation and crying, hypersensitivity to noise, a change in sleeping patterns, or a change in bowel or bladder habits.

Toddlers (18 months to 3 years) are guided by their impulses and do not have the ability to think abstractly. They do not understand the concept of death, but they do know that someone is missing in their world. It is common for children in this age group to ask when the deceased will return, even if they have been given a full and age-appropriate explanation of the absence. Because toddlers have limited verbal skills, they most often react to a loss behaviorally and explore their grief through play. Toddlers who are having difficulty with the loss may exhibit more temper tantrums, become very clingy and fearful, or have nightmares.

Preschool-age children (3 - 6 years) do not yet understand that death is permanent and inevitable. They also believe things quite literally. For example, if told that the deceased "went to heaven," they may ask where heaven is located or if the deceased can eat or sleep in heaven. For this reason, it is important to avoid describing the deceased as "sleeping" or telling a child that a pet has been "put to sleep" because they will have difficulty understanding why the deceased can't wake up, or they may develop a fear of sleep because they are afraid they may not wake up. Children in this age group also have little understanding of the concept of the universality of death; that all living things die. Therefore, they may be preoccupied with thoughts and fantasies of ways in which death can be avoided, fantasies that are sometimes fueled by the unrealistic portrayal of death in children's television programming, particularly cartoons. Preschool-age children are also susceptible to magical thinking – a belief that they are responsible for something because of their bad behavior or because of something they said or did not say. Therefore, it is important to examine the issue of guilt with children in this age group.

Elementary school-age children (7 - 12 years) begin to form a more realistic understanding of death. Children in this age group typically understand the permanency and inevitability of death. However, death is often viewed as more matter of fact than emotional. Elementary school-age children are often fascinated with the mechanics of how the body works and also take more of an interest in the rituals surrounding funerals and burial. Children in this age group are also concerned with how the death will affect their world personally and will most likely exhibit signs of stress behaviorally, through aggression, somatic complaints, and changes in eating and sleeping habits.

Adolescents (12 - 17 years) have a more adult view of death and develop more of an interest in spiritual issues. They are better able to express their feelings verbally, although they generally prefer to talk with their peers rather than a parent or professional. Adolescents who are not coping well with a loss often channel these emotions through anger. This anger can be directed toward someone else or can be turned inward, resulting in risk-taking or self-injurious behaviors.

In helping a child to cope with death, it is important to take into consideration the unique personality characteristics of the child, as well as past experiences with death. Children who have never experienced the death of a friend, family member or pet may be more affected by the loss. However, it is also important to note that a child who experiences multiple losses can experience a grief overload which limits his/her ability to cope. Personality traits can also affect coping. Children who are by nature sensitive or fearful may be overwhelmed by the enormity of the loss and may need more support than others.

When talking with children about death, it is important to begin on the child's level, and be guided by the child's questions. It is good to use simple, straightforward terms that especially stress what has happened to the body. Though it is important for adults to share their religious or spiritual framework with children, unless they also say that the body has stopped working — which means that it is no longer able to see, hear, breathe, eat, or sleep — the child may worry about what will happen when it is buried or may expect the person to return.

If a parent is dying, it is also helpful to explain in detail who will care for the child and where he or she will live. Though adults may take it for granted that the child will live with the surviving parent, the child who has lost a mother or father may fear that the other parent will die or leave, too.

Though we would like to shield children from loss, it is not necessary to protect children from our tears or healthy expressions of grief. Seeing that adults are sad or tearful can help children learn appropriate responses to death and loss.

If children want to attend the visitation or funeral service, they should be allowed to do so in the supportive company of friends and/or family. However, if a child does not want to go, he or she should not be made to do so and should not be coerced or made to feel guilty. Prior to the visitation or service, children who wish to attend should be fully prepared for what to expect. All children, whether they choose to attend or not, can be encouraged to participate in some aspect of the arrangements, such as choosing the pictures to be displayed or making a small gift to put in the casket.

In explaining cremation to children avoid the use of words that may have a frightening connotation such as "fire" or "burn." Instead describe cremation as a process in which the body is taken to a crematory where it is reduced to a fine white powder. Be sure to point out that a dead body feels no pain.

The following list contains some suggestions about healthy ways to guide a child through the experience of grief and loss:

- Talk with the child about death before a crisis occurs, if possible.
- Assess the child's level of understanding by asking questions.
- Let the child's questions and language guide you.
- Answer questions candidly and accurately, keeping in mind the child's age and developmental level.
- Provide opportunities for the child to express feelings (young children are often able to express themselves most comfortably through drawing or playing with dolls, stuffed animals, or puppets).
- Explore the child's spiritual beliefs or faith.
- Explain in advance what will happen at the visitation, funeral, or memorial service, and let the child choose whether or not to attend (if the child wants to view the body, prepare him or her for how the deceased will look).
- Allow the child to leave a small gift, personal item, picture, or note in the coffin if he would like to do so; it is also important to let children assist in making the arrangements by helping choose music, select flowers, or help prepare food.
- Respond lovingly to the child's expressions of anger, frustration, and hostility.
- Recognize that the child will also go through the grieving process, but that he or she will move in and out of it (children's grief occurs in short "bursts," punctuated by periods of apparently normal activity and feeling; grief may also be renewed over the years as the child achieves different levels of development and understands what happened in more mature ways).

Like adults, children cope best when they feel part of a supportive group that loves them. Covenant Care has social workers who will be happy to provide you with more material or work with you and your child. We also provide additional support staff who are available for consultations. Grief provides an opportunity for important learning about life and death. Let us know if we can help you guide your child through these difficult experiences.

HOSPICE CARE

When your focus shifts from seeking a cure to seeking greater quality of life, our hospice services will provide compassionate care to you and your loved ones — helping you make the most of every moment.

For the patient, our primary objectives are to ensure your comfort and dignity while empowering you with choice. As an Open Access hospice provider, Covenant Care offers an exceptional approach to end-of-life care, allowing you to receive the benefits of hospice services while continuing to receive many treatments and medications that are not typically offered by other hospice providers.

From the moment you choose Covenant Care, you become part of our family, so it's only natural that our promise of caring extends beyond the patient to include your loved ones too. Our collaborative team will help manage pain and improve quality of life for the patient, while addressing the needs of the entire family through education and support.

Care will be provided by an interdisciplinary team, consisting of a medical doctor, a nurse practitioner, a registered nurse/case manager, a medical social worker, and a chaplain or other spiritual counselor. Depending on need and preference, a Hospice Aide, a volunteer, a pharmacist, and additional specialty personnel may be involved.

Our nurses are specially trained in pain and symptom management techniques to help alleviate suffering associated with a life-limiting illness. Nurses make regularly scheduled visits to provide skilled patient care and education. Under the direction of our nurses, certified nursing assistants and aides provide personal care services for patients.

Social workers offer physical, emotional and social support to patients and loved ones. They can navigate through insurance concerns and identify tools for financial assistance when needed. Social workers also assist families with advanced directives and funeral arrangements.

The entire team is guided by the patient's individualized plan of care, which is developed and directed by our physicians, who each have advanced training in pain management. These doctors serve as an extension – never a substitute – of the patient's referring physician. Our doctors and nurse practitioners consult regularly with the rest of the patient's care team and make home visits to patients when needed.

Hospice Services

Covenant Care provides the following services to hospice patients and their families:

- Professional staff, on-call when needed, 24 hours a day, 7 days a week
- Skilled nursing services
- Medical social services
- Palliative physician services
- Pharmacist services
- Aide services for personal care such as bathing and dressing
- Medicines which are related to the life-limiting illness for symptom management and pain relief (provided through "Enclara," which contracts with Covenant Care to provide pharmaceuticals for hospice patients)
- In-home continuous care, when there is a medical crisis.
- Medical equipment and supplies, when appropriate and included in the patient's plan of care (provided by contract through a durable medical supply company).
- General inpatient care as appropriate in a contracted nursing facility, one of Covenant Care's Inpatient Hospice Centers, or a hospital setting.
- Counseling for physical, emotional, and spiritual support.
- Bereavement support to the family for a least one year following the patient's death.
- Volunteer services.

Levels of Hospice Care Provided

Routine Home Care

Routine home care is offered to patients who have a life-limiting illness but are not presently experiencing any acute crisis. This is the most frequently delivered level of hospice care. It is available to patients living at home, in an assisted living community or in a nursing facility.

The diagnosis and needs of the patient determine the number of visits from hospice staff and the medications, supplies and equipment provided. At this and every level of care, the patient has access to hospice staff members 24 hours a day.

Respite Care

Respite Care is provided for patients whose symptoms are controlled but whose caregiver requires rest or a short-term absence. Respite Care is provided in a licensed and contracted facility and is limited to five consecutive days. Respite Care can be provided more than once while under the care of hospice.

Continuous Care

Continuous Care is an advanced level of care aimed at providing additional support and assistance to the patient and loved ones during an especially difficult time. It is a more intensive level of care than routine home care and is furnished during brief periods of crisis so the patient can remain in the place of their choosing – thus avoiding the burdens that accompany repeated hospital visits.

Nurses and aides will provide care at the patient's bedside in shifts for a minimum of eight hours and as much as 24 hours a day. The patient will be re-evaluated daily to assess the need for this level of care, as specific criteria must be met to offer Continuous Care.

Inpatient Care

Covenant Care is the only hospice provider in the region with multiple dedicated Inpatient Hospice Centers equipped to address the most complex cases when symptoms are not manageable at home. Our Inpatient Hospice Centers provide high-intensity levels of care during brief periods of crisis, while offering comfort and support to patients and their families during this difficult journey.

Staffed around the clock by Covenant Care's interdisciplinary team of end-of-life experts, our Inpatient Centers offer the entire spectrum of hospice services, emphasizing a plan of care to meet the physical, emotional and spiritual needs of the patient and their loved ones—all in surroundings that are soothing and comfortable.

Our Inpatient Hospice Centers are for short term symptom management, so staff will talk with you and your family about what care is needed once symptoms are controlled.

Centers for Hospice Care

Center for Hospice Care at
West Florida Hospital
8383 North Davis Highway
Pensacola, FL 32514

Center for Hospice Care at
Sacred Heart Hospital
5151 North 9th Avenue
Pensacola, FL 32504

Center for Hospice Care at
Providence Hospital
6801 Airport Boulevard
Mobile, AL 36608

Care Wherever the Patient Calls Home

Our goal is to honor a patient's choice to receive care in their own home or a homelike setting whenever possible; but when managing a life-limiting illness at home is not possible, Covenant Care has established relationships with hospitals, nursing facilities, and assisted living communities throughout Northwest Florida and South Alabama.

One of the hardest decisions that a caregiver may have to make is possible placement of the patient in a care setting outside of the home environment. Usually there is no alternative, but even with that knowledge, caregivers often feel guilty about the decision. If you have to make a decision about placement, we urge you to discuss your options and feelings with your Covenant Care social worker.

Hospice Care provides care and support wherever the patient resides. Some alternative placement settings are:

Adult Living Facilities (ALF):

These facilities are meant for people who are fairly independent, but may need help with cooking, cleaning and some activities of daily living. These facilities usually do not offer skilled nursing care. Some do not have nurses on staff.

Usually when an ALF resident becomes very ill he or she is not able to stay in the facility. **Hospice patients are the exception, under specific circumstances.** With hospice care, and with the facility's agreement, a terminally-ill patient may remain in an ALF until death. Usually a person is already a resident in an ALF when he or she becomes a hospice patient. It is rare for a hospice patient to be placed in an ALF.

Nursing Facilities:

These facilities are meant to provide for more extensive nursing care, including what is known as "Skilled Care." This can range from feeding patients to giving IV medications. Nursing facilities usually specialize in long-term care. Hospice specializes in care of the terminally ill. Both organizations work together to develop a plan of care that carefully spells out who is going to perform what types of care for the patient. The combined strengths of the two organizations work together to create the highest quality and most compassionate care possible for patients residing in nursing homes at this crucial time of their lives.

Hospitals:

Some hospitals only have "acute care" beds. This means that a person with an "acute" problem can be admitted to the hospital, but when that problem is resolved, the person has to return to his or her place of residence. Other hospitals also have Skilled Nursing Facilities (SNF's), Transitional Care Units (TCU's), or Swing Beds, allowing the patient to receive a different level of care but remain in the same bed. These facilities can also deliver longer-term care or can accept hospice patients for placement. Your Covenant Care nurse or social worker will help you decide on appropriate placement. It is important to remember that when a patient elects hospice care, he or she no longer has access to regular Medicare benefits for the terminal diagnosis. **Therefore, before going to a hospital, a patient or caregiver should make every effort to call Covenant Care first, since this may prevent the patient from being responsible for the bill.**

Hospice Care in the Home

Medicines

Your nurse, under the direction of your doctor, will help you in the proper use of medicines for the hospice-covered illness and its prognosis. To make sure bills are handled correctly, new prescriptions and refills must be authorized by the hospice nurse to the pharmacy.

Equipment

Medical equipment, such as a hospital bed, or a walker, that can help you at home will be provided by a contracted provider. Your hospice nurse will help determine what equipment would be most beneficial to you and order it for delivery. Covenant Care will also provide certain other supplies, such as under pads and adult diapers for patients who need them.

Your Care Team

Nursing Services

To make sure our services best meet your needs, a Case Manager will be assigned to oversee your care. This Case Manager, a registered nurse, will be your **primary nurse** and has **special training** in how to care for hospice patients, especially in the areas of pain and symptom management. The nurse may visit every two weeks, once a week, or more often depending on your needs.

On each visit your nurse will:

- Check on your physical health and help with any problems
- Help relieve pain and any other troublesome symptoms
- Teach you and your family about your care, your illness and its different stages
- Review current and new medications with you and your family
- Contact your physician if necessary
- Ask you about the care being given by other team members

Your primary nurse supervises the hospice aides, licensed practical nurses, and volunteers that come into your home. There is also a team of nurses that are available after regular business hours and on weekends. Your nurse and our entire team want you to feel confident and secure about the care we provide.

Physician Services

Every hospice patient has a primary physician who gives the orders for medical care. This may be the physician or nurse practitioner (NP) whom you have known for years, a specialist whom you met during your illness, or a Covenant Care physician or NP who visited you and took over your care after you were admitted. This physician or NP has overall responsibility for your care and is referred to as your “primary physician.” He or she serves as a member of the hospice interdisciplinary team and works with the nurse case manager to coordinate your care. If you wish to see other physicians such as a specialist, the nurse case manager will arrange for this through your primary physician.

The physicians who work for Covenant Care are called Medical Directors and are specially trained in hospice and palliative care. These physicians meet with the interdisciplinary group to review the care plan for each of the patients cared for by that team. If the team decides that a home visit is needed, one of the physicians or NP may be asked to come to your home to help evaluate your situation and to suggest changes in the team’s care plan. These suggestions are then discussed with your primary physician, who will order different medications or treatments if they are needed.

Primary goals for the Medical Directors are to relieve suffering and to achieve the best possible quality of life for the patient. Suffering may be in the form of pain, or it could include other symptoms, such as nausea, constipation, or family distress. Any medications that are prescribed may have to be adjusted over time in order to achieve the greatest benefit with the fewest side effects.

Covenant Care physicians can also evaluate when a treatment is likely to help the patient and family accomplish important goals, or when it will only be a bother with no useful outcome. For example, a patient suffering from cancer may not benefit from medication designed to treat high cholesterol or osteoporosis. Such medications may be safely discontinued, thus reducing the number of medications and the likelihood of side effects.

Hospice Aides

The **Hospice Aide**, also called the “HA,” gives “hands on” help with self-care. An aide is assigned when you, your loved one, and/or a member of the hospice team identify and agree on a need for help with personal care. All care provided by the aide is supervised by your primary nurse. The number of weekly aide visits is increased or decreased according to your needs.

Hospice aides may assist with:

- Bathing (shower, tub, or bed), catheter care
- Dressing
- Hair care (wet or dry shampoo)
- Oral care, including denture care
- Skin care, including back and foot rubs
- Reinforcing wound dressings (A nurse must change the dressings.)
- Nail care - cleaning, filing
- Linen change

Assistance with activity, if requested or recommended by the nurse or physician, including:

- Gentle exercises to arms and legs, walking
- Transfer to a chair, bedside commode, or wheelchair
- Turning and positioning in bed

- Tidying patient area
- Cleaning bathroom after patient bath
- Removing trash from patient area
- Simple meal preparation and assistance with eating

The time allotted for the HA visit is approximately one (1) hour, depending on your needs. If more time is required, the HA must get approval from your nurse.

When giving care, the HA will also:

- Help to keep the patient area safe and comfortable
- Allow the patient to do as much for him or herself as desired
- Show the family how to assist with care
- Be a good listener; offer emotional support
- Talk with the nurse about unrelieved pain, skin breakdown or other problems that may be occurring

Covenant Care aides are some of the best. We hope that you enjoy the tender, loving care that they give. Please direct any concerns or questions about your hospice aide care to the nurse or to the clinical manager who supervises the team.

Social Workers

Social workers are a vital part of the hospice interdisciplinary team. A social worker will visit with you to complete an individual assessment. This assessment will guide us on how we can best assist you with your particular needs. Our social workers are highly-trained professionals who are there to provide support, encouragement, education, and practical assistance with any problems or concerns.

Some of the ways Social Workers may help:

- Providing emotional support to the patient and their loved ones
- Assisting with financial needs by making referrals to other community agencies for additional resources or services
- Assisting with making funeral arrangements
- Assisting with placement for alternative care when needed
- Providing information and assistance with advance directives such as living wills, power of attorney
- Providing education and information
- Assisting with stress management through emotional support and counseling

Trained Volunteers

Volunteer services are available for hospice patients and families. There are a variety of ways a volunteer can help, such as:

- **“Tuck in” volunteers call patients and families each week to be sure that they have supplies, medications and other needs met prior to the weekend**
- **Friendly visits to patients and family members**
- **Respite sitting (for a few hours at a time) to allow the caregiver a rest**
- **Running errands**
- **Simple household chores and maintenance**
- **Sharing interests and hobbies**
- **Honoring/recognizing veteran patients**

Covenant Care volunteers are well-prepared to serve you. They complete a comprehensive screening and training process. You may request a volunteer on a one-time basis or on an ongoing basis, such as respite sitting once a week. Volunteers assist patients wherever they reside and attempt to meet their individual needs. Volunteers are not permitted to dispense medications or provide clinical care; rather their role is to provide emotional support, practical help, and companionship.

Family members who have been served by hospice often choose to become a part of the volunteer program. In addition to patient and family support, volunteers assist in administrative duties, with community outreach events, fundraisers, and in bereavement services.

For more information about Covenant Care Volunteer Services, please call your local office and ask for the Volunteer and Community Relations Manager.

Chaplains/Spiritual Care Coordinators

Covenant Care recognizes that the spiritual situation of the patient is of critical importance and requires extreme sensitivity on the part of the caregiver and others involved. Covenant Care’s Spiritual Care Coordinators are here for spiritual needs at any time.

Through a group of highly professional and dedicated staff, Covenant Care provides spiritual support for the patient at the end of life and for his or her family in their own home. With a commitment to enhancing the patient’s own spiritual resources, the Spiritual Care Coordinators are non-judgmental and open to all forms of faith and expression. They will gladly work together with your regular clergy in meeting your needs. It is our desire to enable patients and their families to reach the highest potential for spiritual awareness during days of intense emotional and physical stress. Home visits, prayer, and counseling serve as means of spiritual support and empowerment. As an integral part of the hospice care team, the Spiritual Care Coordinators are available to serve our patients as they journey through their final days.

Covenant Care’s Spiritual Care Coordinators are here to help you during this time of transition, to provide spiritual support, and comfort however they can.

Bereavement Services

Bereavement Support Services are an integral part of the care provided by Covenant Care. We recognize that the feelings of loss, sadness, and grief following the final illness of a loved one can be overwhelming. We want to help the family members and friends of our patients during this difficult time. To assist those who are grieving, we offer support, education, and comfort for at least one year following a patient's death. Available services include:

- Telephone Contacts
- Home Visits
- Office Visits
- Children's Support Services

- Quarterly Bereavement Newsletter
- Bereavement Support Groups
- Educational Grief Workshops and Seminars
- Bereavement Literature
- Community Resource Referrals
- "Coping With the Holidays" Programs or Education Materials
- Bereavement Volunteer Support

If you have questions or need more information, please do not hesitate to contact Bereavement Services in your local office. You do not have to walk your grief journey alone. We are just a phone call away.

Pharmacy Services

Covenant Care Pharmacy Services work with the patient's attending physician, members of the hospice team, and the Medical Director to establish a medication regimen that is appropriate and effective for each patient under our care.

The process begins during the admission itself, when the admitting nurse may call the pharmacist to review the patient's medications. This is helpful because often patients who have been ill over a period of time are taking medications that don't work well with each other, or are no longer necessary, or can be taken by mouth rather than intravenously, or are available in a less-costly generic form. Since hospice pays for medications related to the primary diagnosis we also need to identify which drugs are related so that we can set up a pharmacy account to cover them. The pharmacist may recommend certain drug changes at that time, and the nurse or Medical Director will follow up with the attending physician to work out these changes.

Some medications may not be related to the hospice diagnosis and related conditions under the Medicare Hospice benefit. In this case, the financial responsibility for any unrelated medications will rest with the patient. Your hospice team will discuss with you whether your medications are related or unrelated.

Throughout the care of the patient, Covenant Care's pharmacist serves as a resource and consultant for drug recommendations or medication issues. Nurses and physicians are able to access the pharmacist 24 hours a day, 7 days a week for help and suggestions. Often, the pharmacist can help to:

- Locate that hard to find drug at one of the many community pharmacies with which we have a contract
- Suggest a drug with less troublesome side effects
- Serve as a liaison with Enclara or the local pharmacy when problems occur

Through periodic review of each patient's medication, the Covenant Care pharmacist also serves as a resource for our Medical Directors and for physicians in the community to determine drugs that might work better and appropriate dosages for the hospice patient. The goal is to ensure that side effects are minimal while symptoms are being controlled. Frequently, drugs can be discontinued so that the patient doesn't have to take so many pills. This helps to simplify the drug schedule.

If you have questions you would like to discuss with the pharmacist, your nursing case manager will help you contact them.

COVENANT CARE CHOICES

Covenant Care Choices operates as a program of Medicare Care Choices and focuses on care for certain types of cancer, congestive heart failure (CHF), chronic pulmonary disease (COPD), and human immunodeficiency virus (HIV).

Under this model, patients are able to access hospice services offered under the Medicare benefit, while allowing for the continuation of curative care services at the same time. This means that the patient does not have to forgo curative treatments to access Covenant Care's services.

However, at any time, you may choose to elect your full hospice Medicare benefit and can be discharged from the Covenant Care Choices program and enrolled into Covenant Care's Hospice Care services.

The Covenant Care Choices team will work in collaboration with the patient and/or all of his or her medical providers to establish shared goals and create a care plan that best fits the patient's needs.

Services Provided

Admission to the Care Choices program is based upon certain eligibility criteria as determined by Medicare Guidelines for the program. Provision and supervision of care will be the responsibility of an interdisciplinary team. Covenant Care provides the following services to patients and their families who are enrolled in the Care Choices program:

Nursing Services

A Care Choices Case Manager will be assigned to oversee the patient's care. This Case Manager, a registered nurse, will be the primary nurse and has special training in how to care for palliative patients, especially in the areas of pain and symptom management. The nurse will visit every two weeks, or depending on your needs.

On each visit, the nurse will:

- Check on the patient's physical health and help with any problems found
- Help relieve pain and any other troublesome symptoms
- Teach patient and family about the illness and its different stages
- Review current and new medications with patient and family
- Contact the patient's physician if necessary
- Ask about the care being given by other team members

The case manager also supervises the personal care aides, licensed practical nurses, and volunteers that come into the home. There is also a team of nurses that are available after regular business hours and on weekends. Our entire team want the patient to feel confident and secure about the care we provide. The nurse will also work closely with all of the patient's medical providers, specialists, durable medical equipment providers, and physicians to coordinate care to best fit the patient's goals and needs.

Physician Services

Every Covenant Care Choices patient has a primary physician who gives the orders for medical care. This one physician has overall responsibility for the patient's care and is referred to as the "primary physician." He or she also serves as a member of the Covenant Care Choices interdisciplinary team which, along with the Covenant Care Choices nurse case manager, works to coordinate care. If you wish to see other physicians such as a specialist, the nurse case manager will arrange for this through your primary physician.

One or two of Covenant Care's physicians meet with the interdisciplinary group to review the care plan for each of the patients cared for by that team. Any suggestions are then discussed with your primary physician, who will order different medications or treatments if they are needed.

COMPANION AND PERSONAL CARE AND HOME HEALTH CARE

We all find peace in the familiar comforts of home. As we age, or when we're faced with a disability or illness, it becomes increasingly important to live independently, surrounded by the people and things that bring us joy and comfort. Covenant Care Home Health Care is equipped to fill a broad range of short- and long-term needs for all ages, no matter where home may be — whether an assisted living facility, nursing home or private residence. Our team of nurses, aides and companions is available 24 hours a day, 365 days a year, offering a caring, supportive presence and services tailored to help each client thrive.

Home Nursing and Therapy Services

Home Health Care provides Registered Nurses and Licensed Practical Nurses for patients recovering from a recent surgery or transitioning home from the hospital who need highly-specialized skilled nursing or therapy services. Working with your doctor and you, our highly qualified staff will plan, coordinate and provide care tailored to your needs.

NOTE: Some services are available in limited areas.

Our services include:

- **Skilled Nursing** – provided by an RN or LPN with training and experience in providing care in the home. The nurse communicates frequently with your physician to update your plan of care. Service may include evaluation of client needs, performance and teaching of skilled nursing procedures; education and teaching of client, family members and caregivers on disease processes; self care techniques and prevention strategies; and coordination of client care and services with your physician and other health care team members. Procedures include wound care, administering infusion therapies, catheter care, etc.
- **Physical, Occupational, Speech Therapy** – provided by a licensed therapist or therapy assistant under the direction of the therapist. Services may include ambulation training, assisting in restoring independence for self care activities, and improve communication skills.
- **Medical Social Services** – provided by a medical social worker. Services may include referral to and coordination with community resources and assistance with living arrangements, finances, and long range planning.
- **Lab Test and Reports** – when ordered by your physician, a Peoples Home Health nurse will come to your home to draw a lab specimen. Results will be sent to your doctor.
- **Supplies** – Medical supplies and therapy services may be required to carry out your plan of care. All medically necessary therapy services or medical supplies must be coordinated with the home health agency while you are receiving Medicare-covered home health services. Commercial insurance requires that you obtain medical supplies from an in-network approved medical supplier. Please contact your carrier for a list of those providers.

Companion and Personal Care

Companion and Personal Care provides Home Health Aides and Certified Nursing Assistants who help with activities of daily living. Some services provided include:

- Medication reminders
- Dignified personal care services, such as bathing and grooming
- Grocery shopping
- Meal preparation
- Housekeeping
- Laundry

Caregivers also provide companionship and a positive, encouraging presence. Staff may stay in the home overnight for additional safety or accompany clients to:

- Doctor appointments
- Recreational outings
- Daily errands

PALLIATIVE CARE

If you're living with a serious illness, Palliative Care can provide relief from pain and alleviate distressing symptoms. Palliative Care provides effective management of and relief from pain, shortness of breath, fatigue, nausea, and other symptoms associated with a serious illness.

Palliative Care can be offered any time during diagnosis and treatment of many long-term conditions. Our focus is to relieve the physical, social, emotional and spiritual suffering that often accompanies a chronic or complex illness. We understand that when your pain and symptoms are under control, you can focus on what matters most – the people and activities that you love.

The Palliative Care program at Covenant Care provides consultations with a physician and/or a nurse practitioner. We will work together with your physician to help manage symptoms and establish goals of care.

Patients receiving Palliative Care can receive treatments to aggressively manage their disease and do not need to have a limited life expectancy. A patient does not need to be homebound to receive this service. Unlike hospice services, which also provide Palliative Care, Palliative Care services do not include medical equipment, medications, disposable supplies or other ancillary staff.

MEMORY CARE

Many Alzheimer's patients and families are struggling to make sense of a disease that doesn't make sense. Lives are turned upside down after the diagnosis, leaving patients and their loved ones unsure where to turn.

Memory Care has developed programs and services to support the needs of patients, caregivers and families living with Alzheimer's disease and other forms of dementia:

- Memory Care Community
- Memory Screenings
- Home Safety Assessments
- Medication Dispensing
- Project Lifesaver
- Support Groups
- Caregiver Assistance Programs
- Education for Caregivers, Community Groups and Healthcare Professionals

These services can give Alzheimer's patients and their families peace of mind as they face the challenges associated with the disease.

Memory Care Community

The Memory Care Community offers 11 state-of-the-art private rooms within a 7,000-square-foot secured wing. The facility is housed on the Joyce Goldenberg Campus in Pensacola.

The Memory Care Community allows residents to age in place, in a tranquil, home-like setting, with skilled staff, innovative programs and optimal living arrangements designed specifically to meet the unique needs of those impacted by dementia.

Developed to provide long-term residential care to those experiencing Alzheimer's disease or a related dementia, the facility also accommodates requests for respite stays, when the center is not at full occupancy, allowing for short-term care provisions as well.

Memory Screenings

Memory screenings are a brief, confidential means of assessing the memory and cognitive functioning of individuals. The memory screen is not a diagnostic tool, but it may suggest a need for further evaluation.

Memory screenings are available by appointment. Request appointment by calling 1.855.CARE.365. We are available to provide memory screenings for groups as well. To arrange a block of time, please contact Covenant Care at 1.855.CARE.365.

Home Safety Assessments

A diagnosis of dementia carries with it a host of considerations when addressing the safety and functionality of the home. Memory Care can help evaluate the unique needs of people living with Alzheimer's within the context of the home environment. From safeguarding specific rooms and making them more dementia friendly, to suggesting interventions for common issues like wandering, sundowning, and difficulties driving, our thorough in-home assessments provide practical strategies in an easy-to-read report. Because we know that safety needs change as the illness progresses, our dynamic assessments can be conducted by our specially-trained staff members at various stages of the disease progression to ensure that safety issues are addressed on an ongoing basis.

In addition to identifying potential problems, our experts can recommend adaptive solutions and resources for necessary modifications that prevent injury and encourage independence.

To make an appointment for a safety assessment, please request services online or call **1.855.CARE.365**.

Medication Dispensing

Take the guesswork out of taking medications. From organizing pills to missed dose alerts and scheduled reminders on when and how to take medications, this service offers greater independence to patients and more peace of mind to their loved ones.

View video: <https://www.youtube.com/watch?v=2NKMxAKLYAc>

Project Lifesaver

Memory Care, in partnership with local law enforcement and search and rescue teams, is proud to offer Project Lifesaver for individuals with Alzheimer's disease, dementia or other brain related disorders for which wandering is a concern.

A person with Alzheimer's disease may wander away from home at any stage of the illness. Many become lost while trying to get "home," wherever that may be. Studies show that approximately 60% of Alzheimer's patients will wander and 70% will wander repeatedly. This can be a very dangerous situation and it represents a critical emergency, since more than half will become injured or die if not found within the first 24 hours.

Project Lifesaver Participants wear a transmitter approximately the size of a watch. Each battery operated transmitter has a unique radio frequency that emits a tracking signal every second, 24 hours a day. When a caregiver notifies 9-1-1 that a person is missing, a trained search team responds to the wanderer's area and begins using a mobile locator tracking system. The radio signal is tracked using specialized Search & Rescue Receivers on the ground or in the air.

Project Lifesaver is a program that's proven to save lives. Currently active in more than 1,400 communities in North America, over 3,100 searches have been performed through the use of Project Lifesaver with no reports of serious injuries or fatalities.

Anyone with a cognitive disorder who is at risk for wandering is an appropriate candidate for this program. Memory Care is the primary enrollment contact for the Project Lifesaver program in Escambia, Santa Rosa, Okaloosa, and Walton counties in Florida. To schedule an enrollment appointment or for more information, call 1.855.CARE.365.

Support Groups For Caregivers

Sometimes caregivers need someone to confide in or guidance in understanding the stages and behaviors associated with Alzheimer's disease. Support groups provide a safe and relaxed environment in which caregivers can share and learn from each other.

Within the group setting, members exchange ideas and experiences, share valuable coping skills, and discuss ways to better care for themselves and their loved ones. Caregivers are most successful when they also try to meet their own needs for physical rest and emotional support.

All of our support group facilitators are trained and receive ongoing professional support and resources.

For more information on support groups, call Covenant Care at 1.855.CARE.365. For a list of support groups, check our events calendar at choosecovenant.org/events/.

Caregiver Assistance Programs

Sometimes caregivers need a listening ear or guidance in understanding the stages and behaviors associated with Alzheimer's disease or a related dementia. Our Telephone Support Services provide reliable information and support for people with memory loss, caregivers, healthcare professionals and the public. Call us during regular business hours to speak with our friendly experts at 1.855.CARE.365.

To ask a question via email, go to choosecovenant.org and click on "contact us."

To schedule an individual meeting or make arrangements for a family consultation, please contact 1.855.CARE.365

Education for Caregivers and Community Groups

CARE Series: (Caregivers Assistance-Reaching out and Educating)

Dementia is an umbrella term that refers to a variety of medical conditions that involve memory loss and other problems with thinking that interfere with a person's day-to-day life. Considering that people are living longer, more families find themselves facing issues related to dementia, memory loss, or Alzheimer's disease. This three-part lecture series will provide an overview of Alzheimer's disease and related dementias, special considerations for caregivers, and resources available to support patients and families through the journey of dementia. For a list of offerings in your community, see the calendar of events at choosecovenant.org.

The Virtual Dementia Tour is a teaching tool that simulates the experience dementia. The VDT allows caregivers to better understand the physical and mental challenges faced by those with dementia. After experiencing this sensory training, caregivers have a greater understanding of the realities of living with dementia. This unique, interactive program has been shown to improve communication and care outcomes. Learning to create a positive environment for those with dementia can only come from attempting to walk in their shoes. For a list of offerings in your community, see the calendar of events at choosecovenant.org.

COVENANT CARE PROMISES & POLICIES

Patient's Bill of Rights and Responsibilities

Federal and State laws require that your healthcare provider or healthcare facility recognize your rights while you are receiving medical care, and that you respect the health care provider's or health care facility's right to expect certain behavior on the part of patients. You may request a copy of the full text of these laws from us. The following is a summary of your rights and responsibilities, as identified by statute, and as integrated with those of the National Hospice and Palliative Care Organization:

Definition of Hospice

Covenant Care is a licensed hospice provider in the States of Florida and Alabama and is certified under the Medicare, Medicaid and TriCare programs. Hospice also receives funding from other sources, including commercial insurance companies. Hospice is a coordinated health care program that provides palliative (comfort) care to patients, as well as supportive care to patients, their families, and their significant others in both home and facility-based settings. A medically-directed interdisciplinary group consisting of the patient, non-hospice-affiliated caregivers, Hospice staff and Hospice volunteers provides physical, social, spiritual and emotional care, with the primary focus on enhancing quality of life for the patient and the family. Our goal is to "add life to days when days can no longer be added to life." Hospice services are available to individuals who:

- Have a life-limiting illness in the opinion of a physician and a hospice medical director.
- Have made a decision with their physician to seek comfort care, rather than curative care.
- Agree to the care plan established through the collaboration of the Covenant Care Team, the patient and the physician.
- Reside within Covenant Care service areas in Alabama or Florida.

As a patient, you have the right to:

- Be cared for by a team of professionals who will provide quality, comprehensive hospice services as needed and appropriate for you and your family (including extended and alternative family).
- Receive information on the scope of services under the hospice benefit and any limitations to those services, including the availability of, and access to services and the hospice team, whose members visit regularly and are on call 24 hours a day, seven days a week. This may include provision of an interpreter if you do not speak English.
- Be provided verbal and written notice of these rights and responsibilities in a language you understand.
- Have impartial access to appropriate and compassionate care and accommodations, regardless of diagnosis, race, national origin, age, gender, religion, creed, disability, sexual orientation, place of residence within the geographical area served by Covenant Care under State Licenses, source of payment or the ability to pay for the services rendered, as identified within Covenant Care's Plan of Care for you.
- Receive a prompt and reasonable response to questions and requests.
- Be involved in developing your hospice plan of care.
- Choose your attending physician and have this individual involved in your medical care.
- Be appropriately informed regarding your health status, diagnosis, planned course of treatment, including benefits and risks, alternatives, and prognosis in order to participate in the planning of your care.
- Accept or refuse those treatments or services as appropriate to your personal wishes, except as otherwise provided by law.
- Be treated with courtesy and respect, with appreciation of individual dignity for your person, family, caregivers and property, as well as protection of your need for individual privacy.

- Have your cultural customs and preferences respected at all times.
- Receive prompt, effective pain management and symptom control.
- Have your family or other caregivers, if available, educated in effective ways of caring for you.
- Receive treatment for any emergency medical condition that failure to treat would decrease your quality of life.
- Expect confidentiality with your clinical record, including social and financial information. Patient information or records will be released only with written consent from you or your agent, or as required by law.
- Voice grievances concerning patient care, treatments, violation of rights as stated in Alabama and Florida law, or respect for person or privacy without being subject to discrimination or reprisal, and have any such complaints investigated by Hospice in accordance with our grievance procedures.
- Be informed in advance of services or of any fees or charges for which you may be responsible. Prior to treatment, you have the right to be given, upon request, full information and necessary counseling on the availability of known financial resources for your care. You have the right to use any insurance or entitlement program for which you may be eligible.
- Receive a copy of a clear and understandable, itemized bill and have the charges explained to you, upon request.
- If you are eligible for Medicare, Medicaid, or TriCare, to know that Hospice is certified for Medicare, Medicaid, and TriCare reimbursement under those respective hospice benefit programs; and to be fully informed concerning the Hospice Benefit under the Medicare, Medicaid, or TriCare hospice benefit programs as they may apply to you.

As a Patient, You and Your Caregiver have the Responsibility to/for:

- Participate in developing your hospice Plan of Care and updating it as your condition or needs change.
- Follow the treatment plan recommended by your physician, Covenant Care and other healthcare providers, as mutually agreed.
- Report any unexpected changes in your condition to hospice.
- Report to hospice whether you understand a proposed course of action and what is expected of you.
- Keep appointments and, when unable to do so for any reason, notify the appropriate healthcare provider and hospice.
- Know your alternatives if you refuse treatment or do not follow a healthcare provider or hospice's instructions.
- Provide hospice, to the best of your knowledge, with accurate and complete health information about present complaints and past medical history.
- Remain under the care of a physician licensed in the state in which care occurs while you are receiving hospice services.
- Assist the hospice staff in developing and maintaining a safe environment in which your care can be provided.
- Fulfill the financial obligations of your health care as promptly as possible, if applicable.
- Follow hospice rules and regulations.

Privacy Statement

COVENANT CARE NOTICE OF PRIVACY PRACTICES

Effective Date: September 23, 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.

Use and Disclosure of Health Information

Covenant Care, Inc., hereinafter referred to as “Covenant,” may use your health information for purposes of providing your treatment, obtaining payment for your care, and conducting health care operations. Your health information may be used or disclosed only after Covenant Care has obtained your written consent. In many cases written consent is obtained upon admission to our services. Covenant Care 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 AFTER YOU HAVE PROVIDED YOUR WRITTEN CONSENT:

To Provide Treatment

Covenant Care may use or disclose health information to aid in your treatment or the coordination of your care. For example, we may disclose information to your physicians, members of the Covenant Care Interdisciplinary Group (nurses, social workers, chaplains, hospice aides and volunteers), hospitals and other healthcare professionals who assist Covenant Care in coordinating the care and services we provide. For example, a physician involved in your care may need to know your current medications and information about your symptoms in order to prescribe appropriate treatment. Covenant Care may also disclose your healthcare information to individuals outside of the organization who are involved in your care. These individuals may include pharmacists, suppliers of medical equipment, or other healthcare professionals that Covenant Care uses in order to provide the full range of services and coordinate your care. Covenant Care may also disclose your healthcare information to those most closely involved in your care, such as family members or clergy whom you have designated, unless you request that we do not do so.

To Obtain Payment

Covenant Care may use or disclose health information to obtain payment for healthcare services. For example, we may include certain health information in invoices to collect payment for the care you receive from third parties, such as Medicare/Medicaid or other health insurance providers. For example, Covenant Care may be required by your insurer to provide information regarding your healthcare status for reimbursement to you or to Covenant Care. We may also need to obtain prior approval from your health insurance provider and may need to explain your need for hospice care and for the services we will be providing to you.

To Conduct Health Care Operations

Covenant Care may use and disclose health care information within the organization to facilitate internal hospice functions and as necessary to provide quality care to you and other patients. Internal functions include, but are not limited to activities such as:

Performance Improvement Activities

- Activities designed to improve health care overall or to reduce health care costs
- Protocol development, case management, and care coordination
- Contacting healthcare providers and patients with information about treatment alternatives and other related issues that do not include treatment
- Professional review and performance evaluation
- Training programs, including those in which students, trainees, or other practitioners in health care learn under supervision
- Training of non-healthcare professionals
- Accreditation, certification, licensing, or credentialing activities
- Review and auditing, including compliance reviews, medical reviews, legal services, and compliance programs
- Business planning and development, including cost management and planning related analyses and formulary development
- Business management and general administrative activities of Covenant Care
- Fundraising for the benefit of the Hospice with certain marketing activities

For example, Covenant Care may use your health information in combination with other Covenant Care patients' information during a survey by the Joint Commission; in the evaluation process to see if Covenant Care is providing the quality of care we expect from our staff; to evaluate the care and services we provide in order to decide how to serve all Covenant Care patients more effectively; to contact you to schedule visits according to your needs; or to contact you or your family as part of community information mailings (unless you tell us you do not want to be contacted).

Covenant Care Centers for Hospice Care

While you are in one of Covenant Care's Centers for Hospice Care, they may disclose certain information about you, including your name, your general health status, your religious affiliation, and your location to people who ask for you by name. Please inform us if you do not want such information disclosed.

For Fundraising and Outreach Activities

We may use certain information about you and the services you received, such as demographic information (including name and mailing address) and the dates that you received treatment to contact you or your family for fundraising activities. You or your legal representative has the right to opt out of fundraising communications from Covenant Care. If you would prefer not to receive fundraising notifications from Covenant Care, please advise our Development and Communications Department, at (850) 438-9714. We will not condition treatment on you agreeing to receive such communications.

For Bereavement Services/Remembrance Celebrations

At your request, Covenant Care may use your name to recognize you as part of our Memorials and Remembrance Celebrations. If you do not wish to be recognized, please notify our Bereavement Department, at (850) 433-2155.

When Legally Required

Covenant Care will disclose your health information when it is required to do so by any Federal, State or local laws.

In the Event of a Breach of Protected Health Information

We may use your contact information to provide legally required notices of unauthorized access, acquisition, use or disclosure of your health information.

When there are risks to public health

Covenant Care may disclose your health information in order to:

Prevent or control disease, injury or disability; report disease, injury, and vital events such as birth or death; and for the conduct of public health surveillance, investigations, and interventions.

To report adverse events and 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.

To notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.

To an employer about an individual who is a member of the workforce as legally required.

To report abuse, neglect or domestic violence

Covenant Care is mandated by law to notify government authorities that are authorized by law to receive such information, if we believe you are a victim of abuse, neglect, or domestic violence. Covenant Care will make this disclosure only when specifically required or authorized by law or when you agree to the disclosure.

To conduct health oversight activities

Covenant Care may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licenser, or disciplinary action. Covenant Care, however, may not disclose your health information without your written HIPAA authorization if you are the subject of an investigation and your health information is not directly related to your receipt of healthcare or public benefits.

In connection with judicial and administrative proceedings

Covenant Care 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. If the request is not court-ordered, we may disclose your health information only when Covenant Care makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

For law enforcement purposes

Covenant Care may disclose your health information to a law enforcement official for law enforcement purposes as follows:

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

For the purpose of identifying or locating a suspect, fugitive, material witness, or missing person

Under certain limited circumstances, when you are the victim of a crime

To a law enforcement official if Covenant Care has a suspicion that your death was the result of criminal **conduct, including criminal conduct at Covenant Care**

In an emergency in order to report a crime

To coroners and medical examiners

Covenant Care may disclose your health information to coroners and medical examiners for the purpose of identifying a deceased person, determining the cause of death or for other duties, as authorized by law.

To funeral directors

Covenant Care 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, Covenant Care may disclose your health information prior to and in reasonable anticipation, of your death.

For organ, eye or tissue donation

Covenant Care may disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes, or tissue for the purpose of facilitating the donation and transplantation.

For research purposes

Covenant Care may, under very select circumstances, use your health information for research. Before Covenant Care uses or discloses any of your health information for such research purposes, the project will be subject to an approval process. Any research study must meet federal privacy law requirements.

In the event of a serious threat to health or safety

Covenant Care may, consistent with applicable law and ethical standards of conduct, disclose your health information if Covenant Care, 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.

For specialized government functions

In certain circumstances, Federal regulations authorize Covenant Care to use or disclose your health information to facilitate specialized government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations, and inmates and law enforcement custody.

For worker's compensation

Covenant Care may release your health information, as authorized by, or to the extent necessary to comply with, state workers compensation laws that govern job-related injuries or illness.

For business associates

Covenant Care may disclose your health information to organizations and vendors that perform functions on our behalf or provide us with services if the information is necessary for such functions or services. Our business associates are required, under contract with us and pursuant to federal law, to protect the privacy of your information and are not allowed to use or disclose any information other than as specified in our contract and permitted by law.

Authorization to use or disclose health information

Other than as stated above, Covenant Care will not use or disclose your health information other than with your written HIPAA authorization. For example, Covenant Care will not use or disclose psychotherapy notes about you, sell your health information to others or use or disclose your health information for marketing communications without your written authorization. If you or your legal representative authorizes Covenant Care to use or disclose your health information, you may revoke that authorization in writing at any time, except if we have already acted based on your authorization.

Your rights with respect to your health information

You have the following rights regarding your health information that Covenant Care maintains:

Right to request restrictions

You may request restrictions on certain uses and disclosures of your health information for treatment, payment or healthcare operations. You have the right to request a limit on Covenant Care's disclosure of your health information to family members or to others involved in your care or the payment of your care. However, Covenant Care is not required to agree to your request, except as described below.

You or your legal representative have the right to request a restriction of disclosure of your health information to a health plan, if the information relates to healthcare items or services for which you have paid in full. Covenant Care is required to agree to all such requests.

If you wish to make a request for restrictions, please make your request in writing to our Privacy Official, Corporate Health Information department.

Right to receive confidential communications

You have the right to request that Covenant Care communicate with you in a certain way. For example, you may ask that Covenant Care only send communications pertaining to your health information to a P.O. Box instead of your home address. If you wish to receive confidential communications, please make your request in writing to our Privacy Official, Corporate Health Information department.

Covenant Care will not request 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 your health information, including billing records. If we maintain a copy of your health information electronically, you also have the right to ask for a copy of your health information in an electronic format. You can also request that we provide a copy of your information to a third party that you identify. All requests to inspect and copy records containing your health information, or to make them available to third parties, may be made in writing to our Privacy Official, Corporate Health Information department. If you request a copy of your health information, Covenant Care may charge a reasonable fee for copying and assembling costs associated with your request as allowable by law.

Right to amend health care information

If you or your legal representative believes that your health information records are incorrect or incomplete, you may request that Covenant

Care amend the records. That request may be made as long as the information is maintained by Covenant Care. A request for an amendment of records must be made in writing to Covenant Care's Privacy Official. The Privacy Official may deny the request if it is not in writing or does not include a reason for the amendment.

The request also may be denied if:

- Your health information records were not created by Covenant Care,
- The records you are requesting are not part of Covenant Care's records,
- The health information you wish to amend is not part of the health information you or your legal representative are permitted to inspect and copy, or
- In the opinion of Covenant Care, the records containing your health information are accurate and complete.

Right to an accounting

You or your legal representative has the right to request an accounting of certain disclosures of your health information made by Covenant Care. This accounting will not include disclosures of information made: (i) for treatment, payment and healthcare operations purposes; (ii) to you or pursuant to your authorization; and (iii) other disclosures for which federal law does not require us to provide an accounting. The request for an accounting must be made in writing to Covenant Care's Privacy Official. The request should specify the time period for the accounting. Accounting requests may not be made for periods of time in excess of six years. Covenant Care will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

Right to a paper copy of this notice

You or your legal representative have the right to a separate paper copy of this Notice at any time, even if you or your representatives have received this Notice previously. To obtain a separate paper copy, please contact our Privacy Official. You or your legal representative may also obtain a copy of the current version of Covenant Care's Notice of Privacy Practices at its website, www.choosecovenant.org.

Duties of Covenant Care

Covenant Care is required by law to maintain the privacy of your health information and to provide to you and your legally-appointed representative this Notice of its duties and privacy practices. Covenant Care is required to abide by terms of this Notice, as may be amended from time to time. Covenant Care 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 Covenant Care changes its Notice, Covenant Care will provide a copy of the revised Notice to you or your legally-appointed representative. You or your legally-appointed personal representative have the right to express complaints to Covenant Care and to the Secretary of Health and Human Services if you or your legally-appointed representative believe that your privacy rights have been violated. Any complaints to Covenant Care should be made in writing to our Privacy Official. Covenant Care encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

Contact person

You can contact our Privacy Official at our Administrative Office, 5041 North 12th Avenue, Pensacola, FL 32504, or by telephone at (850) 433-2155.

Other applicable laws

Other federal privacy laws may apply and limit our ability to use and disclose your health information beyond what we are allowed to do under HIPAA. Florida and Alabama state laws may also limit our rights to use and disclose your health information beyond what we are allowed to do under HIPAA. Below is a list of the categories of health information that are subject to these more restrictive laws and a summary of those laws. These laws have been taken into consideration in developing our policies of how we will use and disclose your health information.

- **Alcohol and Drug Abuse Information:** We are allowed to use and disclose alcohol and drug abuse information only (1) in certain limited circumstances, and/or (2) disclose only to specific recipients.
- **Medicaid Patient Information:** We are allowed to disclose treatment information about Medicaid patients only (1) in certain limited circumstances and/or (2) to specific recipients.
- **HIV/AIDS:** We are allowed to disclose HIV/AIDS information only (1) in certain limited circumstances and/or (2) to specific recipients. We must notify recipients of each disclosure that the disclosed information is protected by state law.
- **Sexually Transmitted Diseases:** We are allowed to disclose sexually transmitted disease treatment information of minors only (1) in certain limited circumstances and/or (2) to specific recipients.
- **Genetic Testing:** We are allowed to disclose DNA testing results only (1) in certain limited circumstances and/or (2) to specific recipients.

Performance Improvement and Corporate Responsibility

Our goal at Covenant Care is to provide care and support that meets the needs and expectations of our patients and their families. We are always eager to hear your suggestions about improving our services. If you have concerns at any time that your rights are not being respected, please bring this to the attention of your nurse, your social worker, or any member of your care team. We would like for you to be delighted with the services you receive from us.

We encourage you to call us at any time with any problem or concern so we can better serve you. Most concerns are followed up the day they are received. Your recommendations will be shared with appropriate staff. In addition, a member of the care team will ask you within 3 to 5 days after admission, how we can best meet your needs and wishes. A satisfaction survey will also be sent to you after our care of the patient ends.

In addition to discussing your needs with the treatment team or with the clinical manager, complaints can be shared with:

**Performance Improvement Director
Covenant Care**

5041 North 12th Ave.
Pensacola, Florida 32504
(850) 433-2155

Our **Corporate Responsibility Program** is designed to detect and prevent violations of organizational or professional standards and of federal, state, or local laws and regulations. If you believe that you have observed professional misconduct or a violation of laws or standards, we encourage you to report this information through an anonymous, confidential hotline at 1-866-691-1967. Your concern will lead to a prompt investigation and report by Covenant Care's Corporate Responsibility Coordinator.

Covenant Care is **Joint Commission accredited**, as part of our commitment to safety and quality care for our patients and families. Covenant Care encourages the active involvement of patients and families in the patient's care and teaches them how to report patient care and safety concerns. To report any concerns that we have not addressed, you may contact the Joint Commission's Office of Quality Monitoring at 1-800-994-6610 or email complaint@jointcommission.org.

The Agency for Health Care Administration also provides a toll-free number for consumers who want to file a complaint against a healthcare facility. We hope that you will be able to resolve any issues that arise by contacting us directly, but if you do not feel satisfied with our response, feel free to contact the toll-free complaint line at 1-888-419-3456 in Florida and at 1-800-356-9596 in Alabama (AL Department of Public Health, Department of Licensure and Certification).

In addition, the State of Florida requests that we make available to all patients or residents for whom we provide care the number of the state's abuse registry, which can be contacted toll-free at 1-800-96-ABUSE. The hotline is confidential and available to report suspected abuse, neglect or exploitation of elderly or disabled adults and children.

We also have a confidential reporting line within our Corporate Responsibility Program, which tracks issues regarding possible violations of professional standards.

Persons who require assistance, assistive devices or accessible meeting rooms in order to attend training or any of our community or patient education classes should contact the Clinical Manager in their area to request assistance. Please call in advance so appropriate arrangements can be made.

Financial Responsibility

Covenant Care financial responsibility advisory for hospice patients having private insurance plans or patients without any insurance

Dear Patient and Caregivers,

Covenant Care is a not-for-profit organization which is required to submit a statement identifying our charges and any co-pay or deductibles for services rendered to patients covered by private insurance. Also, as a condition of our participation in the Medicare program, we are required to evaluate patients who have no insurance coverage for services rendered to them, based on their “ability to pay.” Please note this advisory does not normally apply to Medicare, Medicaid, or most TRICARE beneficiaries.

As our admissions staff has informed you, Covenant Care provides services to all eligible patients, regardless of their ability to pay. We never deny services to patients because they are not able to pay. We do expect, however, that patients without insurance who have some ability to pay will reimburse the organization on a reasonable basis for the services received. We have developed a “sliding scale” method for determining the fair share of payment for patients with little or no insurance coverage. In many cases, the sliding scale determines that a patient is unable to pay any portion. Covenant Care reserves the right to file a claim against a patient’s estate for the charges for unreimbursed care.

Periodically you will receive a letter from us providing an accounting of the services rendered and a summary of reimbursements received. This may also identify the unreimbursed amount for which we are seeking payment. We appreciate your understanding of the requirements under which we must operate and trust this will not in any way detract from your positive view of our program of care. If you have any questions, please contact our Patient Billing Office at (850) 433-2155.

Financial information

Covenant Care, Inc. (Covenant) is a not-for-profit, 501(c) (3) organization operating under both Federal and State statutes and regulations. We are committed to providing services to all eligible patients regardless of their ability to pay. In order to meet this commitment, we depend heavily upon the charitable support of individuals and organizations making tax-deductible contributions, on participation by our patients to the best of their ability, and on the reimbursement we receive from insurance or other benefit providers. This document is intended to assist in your understanding of our funding sources.

Per diem reimbursement

Most of the reimbursement that Covenant Care receives from insurance payers, including Medicare, Medicaid, and standard TRICARE, comes in the form of a “per diem”, or daily payment, for each patient. Under this per diem plan, Covenant Care is required to provide a group of “core services” directly related to the patient’s terminal illness. These include: nursing services, medical social services, physician services and counseling services (such as bereavement, dietary, or spiritual). Other services that are available as needed are volunteer services, physical therapy, occupational therapy, speech-language pathology therapy and homemaker services. Most, but not all, of our private insurance contracts also are structured on a per-diem basis. When an insurance company does not contract with us this way, we look at reimbursement on a case-by-case basis. For other conditions not pertaining to the terminal illness, the patient’s other healthcare benefit coverage continues as it would without Covenant Care’s involvement. For example, a Medicare hospice patient still retains all of his or her normal benefits under Part A unless the care is directly associated with the terminal illness and is identified within the Covenant Care Plan of Care (a detailed listing of all the problems and interventions being addressed by the hospice team).

Medicare

Medicare coverage under the hospice benefit is the single largest source of reimbursement for our services. Under the Medicare hospice benefit, medical supplies, durable medical equipment and drugs related to the terminal illness are also supplied by Covenant Care. All services provided must be consistent with the “Plan of Care” developed by the interdisciplinary group caring for the patient, under the direction of the patient’s attending physician and the Covenant Care Medical Director. Covenant Care does not pay for services that are not included in and authorized by the Plan of Care. If a Covenant Care patient insists upon a service not authorized under the Plan of Care, our policies addressing non-coverage situations will be applied, and the patient or patient’s representative will be notified in writing. A copy of the Covenant Care policy addressing non-coverage, as well as information pertaining to the revocation of hospice benefits or discharge from the hospice program is in the introduction to this service guide.

Medicaid

The Medicaid hospice benefit program is essentially identical to the Medicare program benefits. The additional benefit provided under the Medicaid program, depending upon the patient’s financial eligibility, may be the reimbursement for room and board charges within a participating nursing facility. This is also reimbursed on a per diem basis, and must be identified as part of the hospice Plan of Care.

TRICARE

The TRICARE general coverage is basically the same as the Medicare benefit program except that TRICARE case managers may be utilized. Changes continue to occur in this benefit area and your particular status will be determined upon admission.

Private insurance and managed care

For those patients with private insurance coverage, including those covered by a managed care arrangement, the reimbursement for the services received must be assessed and handled on a case-by-case basis. In some cases, Covenant Care may have negotiated a flat per diem reimbursement program similar to those discussed above under the government programs. In other cases, the patient’s

insurance company may not have agreed to contract with Covenant Care, and insurance coverage must be determined on an individual basis. In some cases, a hospice benefit may exist, but may be limited by a pre-determined maximum or “Cap” amount or a time limitation. When coverage ceases in such cases, Covenant Care will continue to care for patients, regardless of their ability to pay.

Hospice patients with no insurance coverage and limited financial resources

Some of our patients have no insurance benefit coverage. Your social worker may assess your eligibility for Medicaid. If it is determined the patient does not qualify, the sliding scale could be completed. If the patient or family are not able to contribute to the cost of care, this does not create a barrier to admission or to the care provided. All patients will receive the same level of comprehensive services regardless of their ability to pay.

Notes

This section provides a brief overview of our various hospice benefit funding sources. We recognize that this is a very difficult time for our patients and their loved ones, and we want to do all we can to simplify financial issues. In addition, there are several resources in your county that may be able to provide additional financial support such as: assistance with rent or utilities, medications, clothing, food, legal assistance etc. If you have any remaining questions, please contact your social worker or our Patient Accounts Department at (850) 433-2155. Once Covenant Care admits a patient using the criteria for hospice services eligibility, it **may not** discharge the patient at its discretion. There are, **however**, circumstances under which Covenant Care may take such discharge action. These are based upon specific regulatory procedures for patients utilizing their Medicare, Medicaid, or TRICARE benefits. Covenant Care cannot under any circumstance “revoke” a patient’s hospice benefit; only the patient or legal representative can perform that act, since election of the Medicare, Medicaid, or TRICARE Hospice Benefit is the patient’s right. Covenant Care will not request, demand, or pressure a patient to revoke his or her benefit. Covenant Care will fully inform the patient of ramifications of not revoking the

benefit when it becomes apparent the patient may be placing him- or herself in a position in which an increased personal, financial, or other burden may be experienced.

Covenant Care will discharge the patient based upon written orders from the Attending Physician and assist the patient as much as possible in his or her transition to another mode of care. Covenant Care cannot discharge a patient based upon the request of a Consulting Physician. Discharge must be based upon receipt of an order from the Attending Physician. If at any time there is a conflict between Attending Physician, Consulting Physician, or Patient as to a discharge decision, the assistance of the Covenant Care Medical Director or other staff Hospice Physician should be sought by the responsible Covenant Care Clinical Manager.

SPECIFIC SITUATIONS AND DEFINITIONS:

Revocations:

Beneficiaries or their legal representatives may revoke the Medicare, Medicaid, or TRICARE hospice benefit, at any time and for any reason. Normally, the patient's other benefits (such as Medicare Part A) will be reinstated at the time of the revocation. Hospice may not revoke a patient's benefit or pressure a beneficiary to do so. Additionally, revocation of the hospice benefit does not automatically constitute a sufficient basis for the patient to be discharged.

A beneficiary may not designate an effective date of revocation that is earlier than the actual date the revocation is made and signed.

If a patient chooses to revoke his or her hospice benefit, that patient (or legal representative) **must sign a statement** documenting that revocation.

Non-Compliance and Non-Coverage Notifications

When a patient elects treatment that does not comply with the hospice plan of care, Covenant Care should counsel the beneficiary on his or her option to revoke the hospice benefit, and provide information on any advantages or disadvantages of the decision the patient may make. The following provides examples of non-compliance with the hospice plan of care:

The patient seeks curative treatment(s) for the terminal illness; or The patient seeks treatment in a facility that does not have a contract with Covenant Care; or The patient seeks treatment(s) that are not in the Covenant Care Plan of Care or are not pre-approved by Covenant Care.

If a patient seeks treatment related to the terminal illness, but which is not consistent with the Covenant Care Plan of Care, or is seeking/receiving care provided in a non-contracted facility or non-contracted entity, Covenant Care will not be responsible for any expenses incurred by such treatment. The Business Services Division will send a copy of this notification letter to the Medicare, Medicaid, or TRICARE intermediary and the patient's physician. If the patient is covered under one of Covenant Care's agreements with a third-party payor, that company will be notified utilizing the same procedures. The case manager shall file a copy in the patient's chart. If the patient refuses to sign an acknowledgment of receipt of the notification, such refusal should be documented on the form and in the patient's record. If the care is being provided in one of Covenant Care's contracted facilities, the Business Services Division will immediately notify that facility of the non-coverage situation. Covenant Care will make reasonable attempts to notify non-contracted facilities or entities, but the primary burden of that responsibility lies with the patient.

If a patient insists Covenant Care file a claim on his or her behalf for services received under a Non-Coverage situation, Covenant Care will do so but will again advise the fiscal intermediary of the non-coverage status of the claim. The patient should expect to receive a formal determination from the appropriate fiscal intermediary.

Discharge

Covenant Care must ensure that its procedures for discharging patients are not and cannot be interpreted as "dumping." Covenant Care must clearly document the reason the discharge was necessary. Covenant Care can discharge (not revoke) a patient for the following reasons:

The patient is determined to be **no longer terminally ill**, with a life expectancy of six months or less in Alabama, and one year or less in Florida.

The patient **moves out of the Covenant Care geographically defined authorized service area.** This includes the circumstance in which a patient leaves the Covenant Care service area and is admitted to a facility, either inside or outside the State of Florida or the State of Alabama, which is outside Covenant Care's licensed service areas. In that case, the patient is in fact "residing" outside the Covenant Care service area, and Covenant Care should take steps immediately to attempt the transfer of the patient to a hospice in that service area, assuming the patient wants to continue hospice services and desires to be transferred to another hospice. The Business Services Division shall also notify cognizant fiscal intermediaries or insurance plans of the transfer. If a hospice refuses to accept a patient under such circumstances, both the fiscal intermediary and the Florida Agency for Health Care Administration or Alabama Department of Health should be immediately informed. Covenant Care's Business, in concert with the Operations Division, is responsible for these notifications as well.

If the **safety of the patient or the Covenant Care staff is compromised**, Covenant Care must make every reasonable effort to resolve the problem(s) satisfactorily before it considers discharge an option. All efforts to resolve the problem shall be documented in detail in the patient's clinical record, and the Business Services Division shall notify the fiscal intermediary and the State of Florida Agency for Health Care Administration or Alabama Department of Health of the circumstances surrounding the impending discharge.

If the **patient enters a non-contracted healthcare facility** in the Covenant Care service area, and all options have been pursued (such as: a contract is not obtainable, patient chooses not to transfer to a facility with which Covenant Care has a contract, transfer to a Covenant Care Center for Hospice Care is not available or acceptable, or the patient cannot be transferred to a hospice with which the nursing facility has a contract), Covenant Care can then discharge the patient. Covenant Care must make the notifications as outlined above.

Transfer of Patients within Covenant Care System

Since Covenant Care is licensed to provide services in both Florida and Alabama, it is not unusual for admitted patients to move to another location within the Covenant Care service areas. In Alabama, each of the Covenant Care offices is separately licensed by the State of Alabama. In Florida, the offices are not separately licensed, but appear instead on the overall license of Covenant Care, which shows Pensacola as the corporate headquarters. Additionally, in Florida, Covenant Care operates in both District 1 and Sub-district 2A & 2B and has offices in each of these areas. A patient's residence or home is defined as the patient's current place of residence, including a private residence, facility, hospice residential/inpatient facility, or other place of permanent or temporary residence.

If a Covenant Care patient relocates or changes his or her residence from a Covenant Care service area/office in the State of Alabama to a Covenant Care service area in the State of Florida (or vice versa), that patient would need to be transferred in accordance with standard procedures for transfer of hospice patients, just as if the patient were coming from another hospice program. In other words, we would discharge and readmit the patient, and the patient would receive a new patient number.

If a Covenant Care patient relocates or changes his or her residence from the service area of one licensed Covenant Care office in Alabama to another licensed Covenant Care office in Alabama, the same transfer procedures discussed above would apply, and the patient would receive a new patient number, except between Baldwin County/Daphne and Mobile. The offices are licensed separately, but are covered by a single provider number; therefore, the procedure for transferring a patient between Mobile and Baldwin would be the same as for Florida, described above.

If a Covenant Care patient relocates or changes his or her residence in the State of Florida from the service area of one Covenant Care office to the service area of another office within the same District or Sub-district, the patient would be transferred to that new office, but would not be discharged and readmitted,

and would retain the same patient number.

If a Covenant Care patient relocates or changes his or her residence in the State of Florida from the service area of one Covenant Care Office, in one District or Sub-district, to the service area of another office, in a different District or Sub-district, the patient would be transferred to that new office, but would not be discharged. However, this transfer between Districts or Sub-districts would be counted as an additional admission in the periodic reports provided to the State of Florida, but the patient would retain the same patient number. This counting procedure is implemented in accordance with AHCA directives.

The Business Services Division must be notified immediately of any discharges and readmissions in order to ascertain in which benefit period, as applicable, the patient may be. All discharges and readmissions will be counted as separate for both State and Federal regulation purposes. In the case of a discharge and readmission, a copy of the patient's records will be provided to the Corporate Office, while the original record of the patient should be transferred to the new, receiving office. Billings, as appropriate, should occur only once for the day of transfer, and if the patient is being admitted for inpatient care, the billing should be at the inpatient rate.

Hospice staff must fully and completely document the circumstances of all transfer cases.

Special circumstances

Patients who are admitted to a Military or Veterans inpatient facility should not be automatically discharged from Covenant Care, as long as the inpatient facility is within the geographic service area of Covenant Care and, the basic admission criteria continue to exist. Covenant Care cannot contract for inpatient services within Military or Veterans Administration inpatient facilities, but can continue to provide hospice services to such patients. The Business Services Division should follow current regulations regarding any billing to federal or state reimbursement sources. Billings to commercial insurance companies on patients who are admitted to a government hospital will be on a case-by-case basis.

Patients being admitted in any service area that have

a reasonable potential to be admitted to any hospital in that area which will not contract (participate) with Covenant Care shall be informed of this situation, and such shall be carefully documented in the patient's medical record. Any admission to a non-contracted hospital will constitute a "non-compliance" situation and should be dealt with in accordance with the procedures outlined in this policy.

At times, patients are admitted to an inpatient facility (and particularly a hospital) for a condition unrelated to the terminal illness. For example, a patient with cancer of the lung may fall while shopping and fracture a hip. If the patient is admitted to a hospital in our service area with which we enjoy a contractual relationship, we will continue to follow the patient in the hospital, billing at the appropriate "routine home care" rate.

Executive Leadership should be advised/consulted on all potential or actual non-compliance situations. All discharges from Covenant Care not related to the death of the patient and all non-compliance cases shall be the subject of a review by the Performance Improvement Team to ensure compliance with rules, regulations, and this policy. A report of the results of such focused reviews will be provided to Executive Leadership.

Medicare appeal

Covenant Care will discharge a patient if he or she is no longer considered eligible for the Medicare hospice benefit. Medicare states, "If your hospice program or doctor believes that you're no longer eligible for hospice care because your condition has improved — and you don't agree — you have the right to ask for a review of your case. Your hospice provider should give you a notice that explains your right to an expedited (fast) review by an independent reviewer an independent reviewer contracted by Medicare, called a Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). This notice lists your BFCC-QIO's contact information and explains your rights. You can also visit [Medicare.gov/contacts](https://www.medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to get the phone number for your BFCC-QIO."

GLOSSARY OF TERMS

ADLs – Activities of Daily Living: Bathing, dressing, eating, toileting, etc.

ALF- Assisted Living Facility: A facility meant for people who are fairly independent but need some assistance (e.g. cooking or housekeeping services).

Advance Directive: Specific instructions made by a patient on how/what medical decisions are to be made should they be unable to communicate their wishes.

Agitation: Extreme restlessness and or confusion.

Apnea: Irregular breathing.

Anorexia: Not feeling hungry or wanting to eat.

Attending Physician: A patient's primary doctor.

Bereavement: A state of loss.

Biomedical Waste: Disposable items saturated with large amounts of blood or other body fluids that contain visible blood, which requires special handling.

Cardiac: Having to do with the heart.

Care Plan: A written plan that explains what the care goals are and how the team plans to meet those goals.

Case Manager: Primary nurse assigned to care for a patient.

Catheter: A tube that carries fluid from one place to another, often placed in the bladder for patients who cannot control the flow of their urine.

Certification: A statement from a physician that a patient qualifies for hospice care.

Chronic illness: A health condition someone has lived with for many years.

CMS: Centers for Medicare and Medicaid Services: A U.S. Federal Agency.

CPR: Cardiopulmonary Resuscitation: First aid meant to keep blood circulating in a person whose heart has stopped beating.

Comfort Pak: Emergency medications that may be placed in the home to treat symptoms that develop suddenly.

Constipation: Not having a bowel movement for several days, hard stool that is difficult to pass.

Continuous Care: A higher level of care provided in the home to treat a medical crisis.

Controlled Substances: Medications, normally narcotics, which fall under control of federal agencies as to their use and or disposal.

Core Services: Services that must be offered by a hospice (e.g. Physician, Nurse, Social Worker, Chaplain, Hospice Aide, Bereavement).

Curative Care: Treatment that is meant to cure a disease/illness.

DME: Durable Medical Equipment: Medical equipment such as wheelchairs, hospital beds, and oxygen tanks designed to be used more than one time.

DNR: Do Not Resuscitate: A physician's order to not start CPR.

Diarrhea: Frequent (more than 3) loose/liquid stools per day.

Discharge: Hospice may discharge a patient under certain circumstances (e.g. the patient is no longer terminally ill, patient moves out of service area, etc.).

Disoriented: Confused.

Decubitus: A pressure sore/wound.

Dyspnea: Feeling short of breath.

Edema: Swelling.

Elect: To choose. A person chooses hospice care by signing an election form.

Enteral: Involving the intestines or digestive tract.

Fatigue: Feeling tired or weak.

Grief: Response to a loss.

Health Care Surrogate/Proxy: Someone chosen by a patient to make healthcare decisions for the patient.

Hepatic: Having to do with the liver.

HIPAA: Health Insurance Portability and Accountability Act: laws and regulations designed to protect the confidentiality of patient health information.

- Holistic:** Health care that attends to all areas of a patient's needs (e.g. physical, emotional, spiritual).
- Hospice:** Originally meant to refer to a place for travelers to rest. Now used to refer to care provided to people with a terminal illness to manage symptoms and provide support.
- Hospice Aide:** A hospice employee trained to provide personal care services to a patient (e.g. bathing, dressing, etc.).
- IDG: Interdisciplinary Group:** Care team made up of doctors, nurses, social workers, hospice aides, chaplains, volunteers and bereavement counselors.
- Imminent:** Used to describe a patient who is expected to die very soon.
- Incontinent:** To lose control of your bowel or bladder.
- Infection Control:** Steps taken to decrease the spread of germs/illness.
- Inpatient Care:** A higher level of care offered in a facility (e.g. hospital, nursing home or hospice inpatient unit) and provided for a short time to treat symptoms that cannot be managed at a routine level of care.
- Insomnia:** Being unable to sleep.
- Living Will:** A document completed by a patient indicating what types of treatment they want to receive, should they be unable to communicate their wishes themselves.
- Medicaid:** Health insurance program managed by the state, with some funding from the federal government, for those people who qualify. Can include hospice care if certain requirements are met.
- Medical Director:** A physician who oversees a program.
- Medicare:** National health insurance program for the elderly and disabled, managed by the federal government. Can include hospice care if certain guidelines are met.
- Medication Reconciliation:** Checking that the right medications, at the right amount, are present and being taken as the doctor ordered.
- Narcotic:** Strong medicines known as opiates that are meant to treat pain or cause sleep.
- Nausea:** Upset stomach, feeling like you are going to throw up.
- Non Compliance:** To not follow instructions/plan.
- Non Coverage:** Not paid for.
- Oncology:** Field of medicine specializing in the treatment of tumors/cancer.
- Oral:** Having to do with the mouth.
- Palliative:** Healthcare that is focused on reducing symptoms such as pain, shortness of breath, rather than curing the illness.
- Palliative Performance Scale:** A measurement tool that shows how much assistance a patient needs with basic activities of life such as bathing, dressing, walking and eating.
- Per Diem:** A set dollar amount of reimbursement paid per day.
- Prognosis:** A prediction of a probable course/outcome.
- Pulmonary:** Having to do with the lungs.
- Recertification:** Physician's statement that a patient should continue to get hospice care based on their current condition.
- Renal:** Having to do with the kidneys.
- Respite Care:** A level of care designed to give caregivers a break from taking care of the patient by placing the patient in a nursing facility for a few days.
- Revoke:** To cancel or discontinue.
- Revocation:** A document signed by a patient or their representative canceling hospice care.
- Routine Home Care:** Basic level of hospice care provided in a patient's home, wherever they may live.
- Saliva:** Spit.
- Seizure:** Uncontrolled muscle movement.
- Sharps Container:** A hard container used to store used needles or other sharp objects that have blood on them.
- SNF: Skilled Nursing Facility:** A nursing facility that provides round-the-clock nursing staff.
- Suppository:** Medicine that is usually inserted into the rectum.
- Vomiting:** Throwing up.

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APPENDIX

Disposal Of Narcotics, Controlled Or Dangerous Substances and All Other Prescription Medications

PURPOSE

To ensure the appropriate disposal of narcotic controlled substances and other patient prescription medications in accordance with applicable state and federal law and standards of practice.

PROCEDURE

Upon admission to hospice, general medication management including methods of controlled (C-II - V) medication destruction will be discussed with the patient/family/caregiver. At the time of admission, the patient or the patient's health care surrogate is requested to sign documentation that they have been informed of Covenant Care's Medication Disposal procedure.

- 1) If the responsible party agrees via signature, the Covenant Care nurse may assist in the disposal of the controlled substances within the patient's residence and in the presence of a witness as described below. Information on proper medication disposal should be re-presented at the time of medication discontinuation, expiration of medication, or patient's death.
- 2) The Covenant Care nurse may assist by providing kitty litter or other substances for the family to use to safely dispose of medications, or by providing Rx Destroyer containers. The following steps should be used in the process of medication destruction:
 - a) Medication-specific instructions:
 - i) Pills, liquids, and infusion medications – If using RX Destroyer, put unused or unwanted medications into the bottle, place cap back on and invert bottle and wash digestion solution over medications. If not using Rx Destroyer, pour unused or expired solid medications into a sealable plastic bag (i.e. Ziploc®); add unused or expired liquid medication or small amount of water or soda to begin dissolving solid medications. Then add kitty litter, sawdust, dirt, vinegar, or used coffee grounds to the plastic bag; seal bag; place sealed bag into a nondescript, tied plastic bag, coffee can, or detergent bottle, and place into garbage.

NOTE: Prescription drugs that are individually packaged should be removed from the wrapping before destroying.
 - ii) Pumps/infusion medications – Disconnect from pump/line and dispose of medication as recommended. Flush medication in toilet if appropriate per FDA, pour into RX Destroyer or discard in plastic bag as mentioned above.
 - b) Medications are never to be disposed of in the trash unless they are properly destroyed, covered, and disguised.
 - c) Whenever possible, it is best to avoid flushing medication(s) in the toilet, but certain medications with high abuse potential are recommended to be flushed by the FDA and DEA. An FDA approved list can be found at: <https://www.fda.gov/downloads/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/UCM337803.pdf>

NOTE: Any discrepancy in drug quantities must be reported immediately to the Clinical Manager or the Regional Director of Operations.

- 3) During each nursing visit, medications must be reviewed and reconciled with the EMR. Medications should be inspected for accuracy and expiration dates. Any expired or discontinued medications should be disposed of per the following instruction. Covenant Care is responsible for providing the following education on proper prescription drug disposal:
- a) The patient's family and caregivers should be encouraged to take unneeded or expired medications to a DEA authorized disposal site. A list of locations can be found at:
<http://www.dep.state.fl.us/WASTE/categories/medications/pages/disposal.htm>
 - i) The DEA has also authorized prescription drug disposal programs by mail. Prepaid envelopes for disposal through the USPS are available for purchase at many pharmacies.
 - b) If an authorized disposal site or mail disposal program is not available locally, the patient's family and/or caregiver should be educated on proper medication disposal technique as follows:
 - i) It is recommended to wear gloves when disposing of medications that could be absorbed through the skin (e.g., transdermal patches, ointments, gels, etc).
 - ii) Mark out the patient's name and prescription number with dark marker before throwing out empty bottles or containers.
- 4) Documentation of the medications to be disposed of should be recorded on the Covenant Care form entitled "Medication Disposal" and a copy of the form should be given to the family/caregiver(s).
- 5) Under no circumstances shall any non-destroyed medications, including narcotics and controlled substances, be removed from the patient's place of residence by hospice staff or representatives.
- 6) If caregiver refuses to agree to medication destruction, the hospice nurse shall:
- a) Instruct the caregiver regarding appropriate medication destruction
 - b) Document the medications and the amount that should be destroyed
 - c) Document the name of the person refusing the medication destruction and obtain signature on the "Medication Disposal" form, then submit form for filing in the patient record.
 - d) DO NOT remove the medications from the home.
 - e) Inform the refusing party that the nurse is obligated by law to report the presence of medication in the home which becomes contraband once the patient has died.
 - i) Federal law prohibits the transfer of prescription medications to any person other than the person for whom it was prescribed.
- 7) If a Covenant Care staff member encounters any circumstance in which they are concerned as to the appropriate actions to take, they should remove themselves physically from the situation and contact the Clinical Manager, Regional Director of Operations, or Administrator of Hospice Operations.

Advance Directive Policy Summary

All adult patients or a patient's surrogate, proxy or other legal representative will be informed upon admission of their rights under law to accept or refuse medical treatments and to make their own decisions regarding life-sustaining treatment through a living will or other advance healthcare directive.

The requirement for discussion of advance directives will be carried out primarily by the Covenant Care admission team. Such discussion will be clearly documented in the patient's medical record. Advance directive forms are provided in the Patient/Family Handbook, and extra copies are available.

The Social Work department will be responsible for appropriate follow-up and for responding to inquiries.

Provisions of care will not be based upon whether the individual has executed an advance directive. Patients and or their representatives will be informed of the actions Covenant Care staff will take in the event of a medical emergency based on the patient's wishes (e.g. CPR).

The patient is responsible for providing the agency with a copy of his/her directives. Any directives which were formulated previously and have not been revoked will be honored by Covenant Care to the full extent allowed by law.

Any advance directives executed by the patient will be made part of the medical record. These documents will be sent with the patient if he/she is transferred to another healthcare facility or provider.

Education for the staff, community, or individuals regarding advance directives will be available upon request.

You have the right to call the hotline if you have concerns about the implementation of your advanced directives.

Covenant Care Corporate Responsibility Hotline: 1-866-691-1967




Pain Diary

Patient Name

Date	Medication Taken	Amount	Time	Pain Severity	Description of Pain*	Location of Pain	Pain Severity After 1 Hour

*Pain descriptors include: throbbing, shooting, drilling, sharp, dull, pinching, cramping, pulling, burning, tingling, stinging

 The Enclara Pharmacia ComfortPak™		The ComfortPak™ is a box of commonly used medicines to manage urgent symptoms. Each medicine is to be taken separately according to the directions on the prescription label and those provided by the nurse or prescriber. This ComfortPak was made for the patient receiving it and may or may not contain all of the medicines listed below.	
Acetaminophen suppositories 650 mg (Quantity: 4)	Haloperidol liquid 2 mg/mL (Quantity: 15 mL)	Lorazepam tablets 0.5 mg (Quantity: 10)	Prochlorperazine tablets 10 mg (Quantity: 6)
Bisacodyl suppository 10 mg (Quantity: 2)	Hyoscyamine SL tablets 0.125 mg (Quantity: 12)	Morphine sulfate concentrate oral solution 20 mg/mL (Quantity: 15 mL)	

General Information

Storage for all medicines in the ComfortPak

It is recommended to store the sealed ComfortPak on the top shelf in the refrigerator. Keep the box and contents out of the reach of children. Do not store in the bathroom or in heat or light.

Precautions for all medicines in the ComfortPak

- Medicines in the ComfortPak should only be used when instructed to do so by the nurse or prescriber.
- The nurse or prescriber will provide information on which medicine to take, how to take it and when to take it.
- If symptoms do not improve or if they become worse, notify the nurse or prescriber.
- The medicines in the ComfortPak may cause drowsiness, dizziness, or make it hard to concentrate. It is recommended to get up slowly from a sitting or lying down position to avoid lightheadedness.
- Tasks that require alertness should not be attempted when taking medicine from the ComfortPak.
- The nurse and prescriber should be informed about other medicines, herbs, treatments, or alcohol the patient is taking before the medicines are used from the ComfortPak.
- Do not share any medicine from the ComfortPak with anyone other than the person for whom the ComfortPak was prescribed.

Missed Doses for all medicines in the ComfortPak

If a dose of medication is missed, it should be taken as soon as remembered. If it is almost time for the next dose, skip the missed dose and take the regular dose on time. Do not double the dose.

Disclaimer

This is a summary and does not contain all possible information about the products. For complete information about this product or specific health needs, please ask a healthcare professional. Always seek the advice of a healthcare professional if there are any questions about the products or the medical condition. This information is not intended as individual medical advice and does not substitute for the knowledge and judgment of a healthcare professional. This information does not contain any assurances that this product is safe, effective, or appropriate.

Questions

If there are any questions or concerns regarding the proper usage, storage, or potential side effects of this medication, please call an Enclara Pharmacia pharmacist at **1-866-703-1730**.

Acetaminophen (Acephen™) Suppositories

Common uses

Used for mild to moderate pain and to reduce fever.

Let the prescriber know if any of these conditions are present:

Liver disease, Kidney disease, Hepatitis, Phenylketonuria, Anemia, Infection, Intake of more than 3 alcohol-containing drinks per day, An unusual or allergic reaction to acetaminophen, aspirin, other medicines, foods, dyes or preservatives.

How to use this medicine

This medicine is a rectal suppository. This medicine is not to be swallowed. The individual administering the suppository should wash their hands and wet the suppository. To insert the suppository, the patient should be lying down on their side and the pointed end of the suppository should be inserted with a finger well into the rectum. Hands should be washed thoroughly before and after placing the suppository into the rectum.

Notify the nurse right away if any of the following or if other serious effects occur

Skin rash or hives, fever or sore throat, difficulty breathing, wheezing, nausea, vomiting, bloody or black, tarry stools, stomach cramps and pain, difficulty urinating, unusual tiredness, unusual bleeding or bruising, pinpoint red spots on the skin.

Bisacodyl (Dulcolax®) Suppositories

Common uses

To treat constipation by stimulating bowel movements. Bowel movements are generally produced within 15 minutes to 1 hour of use.

How to use this medicine

This medicine is a suppository that is for rectal use only. Remove foil wrapping and insert suppository well into the rectum, pointed end first. Retain for at least 15-20 minutes.

Other precautions for this medicine

If the suppository seems soft, hold under cold water with foil wrapper on for one to two minutes.

Side effects

Some of the following side effects may occur

Diarrhea, rectal itching/burning/swelling, bloating, lower stomach discomfort or cramps

Notify the nurse right away if any of the following or if other serious effects occur

Muscle weakness, severe nausea/vomiting

Haloperidol (Haldol®) Liquid

Common uses

To treat agitation, nausea, and vomiting. It may be used to treat other conditions as determined by the prescriber.

How to use this medicine

This medicine is a concentrated liquid. Measure liquid carefully with a dropper or oral syringe. This medicine may be swallowed. If swallowing

is too difficult, this medicine may also be placed under the tongue. This medicine can also be mixed with a small amount of water, milk, juice, applesauce, or pudding.

Side effects

Some of the following side effects may occur

Dry mouth, constipation, drowsiness, blurred vision, restlessness, seizures, difficulty sleeping, nausea, vomiting, decreased sweating, or dizziness.

Notify the nurse right away if any of the following or if other serious effects occur

Unusual weakness, difficulty urinating, abdominal pain, rash, palpitations or rapid heartbeat, painful erection, changes in behavior or confusion, jaundice, unusual tremors or movements of the hands or feet, continued feelings of restlessness or inability to sit still.

Hyoscyamine (Levsin®) SL Tablets

Common uses

To decrease secretions and saliva production. It may be used to treat other conditions as determined by the prescriber.

How to use this medicine

This medicine is best used when placed under the tongue to manage various symptoms (see Common Uses). This medicine may also be swallowed if placing under the tongue is too difficult.

Side effects

Some of the following side effects may occur

Dry mouth and/or eyes, blurred vision, constipation, dizziness, drowsiness, decreased sweating, or difficulty sleeping.

Notify the nurse right away if any of the following or if other serious effects occur

Unusual weakness, vomiting, difficulty urinating, abdominal pain, rash, palpitations or rapid heartbeat, or changes in behavior such as unusual excitement or confusion.

Lorazepam (Ativan®) Tablets

Common uses

To reduce anxiety, nausea, vomiting and difficulty falling asleep.

How to use this medicine

Tablets should be taken by mouth with a full glass of water or as directed by the nurse or prescriber.

Other precautions for this medicine

This medicine should not be stopped or discontinued without first checking with the nurse or prescriber. Sudden discontinuation of this medicine may result in withdrawal symptoms.

Side effects

Some of the following side effects may occur

Drowsiness, dizziness.

Notify the nurse right away if any of the following or if other serious effects occur

Extreme sedation, confusion, unsteadiness, problems walking, memory problems, agitation, anger, or changes in behavior.

Morphine Sulfate (Roxanol®) Concentrate Oral Solution

Common uses

positions in bed or wound dressing changes. The effects of morphine sulfate solution usually last for 2 to 4 hours.

How to use this medicine

This medicine is a concentrated solution. Measure liquid carefully with a dropper or oral syringe. This medicine may be swallowed. If swallowing is too difficult, this medicine may also be placed under the tongue. This medicine can also be mixed with a small amount of water, milk, juice, applesauce, or pudding.

Other precautions for this medicine

Tell the nurse or prescriber about any severe allergic reactions to this medicine or similar medicines before taking this medicine.

Side effects

Some of the following side effects may occur

Drowsiness, dizziness, stomach upset, sweating, flushing, itching, or constipation.

Notify the nurse right away if any of the following or if other serious effects occur

Severe sedation, muscle twitching, confusion, hallucinations, personality changes, trouble breathing, signs of allergy (rash, hives), or tremors.

Prochlorperazine (Compazine®) Tablets

Common uses

To reduce nausea and vomiting.

How to use this medicine

Tablets should be taken with a full glass of water or as directed by the nurse or prescriber.

Side effects

Some of the following side effects may occur

Drowsiness or unusual tiredness, dizziness, constipation, headache, dry mouth, blurred vision, stomach pain, rash, nasal congestion, or sensitivity to light.

Notify the nurse right away if any of the following or if other serious effects occur

Confusion, vision problems, slurred speech, unusual/excessive tiredness, muscle stiffness, lip smacking, problems with urination or coordination, unusual tremors or movements of the hands or feet, continued feelings of restlessness or inability to sit still.

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[illegible]

FLORIDA LIVING WILL DECLARATION

Declaration, made this _____ day of _____, 20_____.

I, _____, willfully and voluntarily make known my desire that my dying not be artificially prolonged under the circumstances set forth below, and I do hereby declare that, if at any time I am incapacitated and

_____ I have a terminal condition

Initial

OR

_____ I have an end-stage condition

Initial

OR

_____ I am in a persistent vegetative state

Initial

And if my attending or treating physician and another consulting physician have determined that there is no reasonable medical probability of my recovery from such condition, I direct that life-prolonging procedures be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying, and I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

It is my intention that this declaration be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and to accept the consequences for such refusal.

In the event that I have been determined to be unable to provide express and informed consent regarding the withholding, withdrawal, or continuation of life-prolonging procedures, I wish to designate, as my surrogate to carry out the provisions of this declaration:

Name: _____

Address: _____ City: _____ State _____ Zip Code: _____

ADDITIONAL INSTRUCTIONS (OPTIONAL):

ORGAN DONATION (OPTIONAL)

FLORIDA LIVING WILL DECLARATION

I provide the following instructions regarding donation of my organs and tissues at the time of my death.

(INITIAL ONLY ONE)

(____) I want to donate all of my organs and tissues.

(____) I want to donate the following specific organs and tissues:

DECLARANT'S SIGNATURE

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

SIGNATURE _____

Address: _____ City: _____ State _____ Zip Code: _____

(Date of Birth)

(Social Security Number)

WITNESS STATEMENT

I declare that the person who signed this document is personally known to me to be the Declarant; that the Declarant signed this document in my presence; or directed another person to sign this document in my presence; and that I have signed this document in the presence of the Declarant and also in the presence of the other witness, and that the Declarant appears to be under no duress, fraud or undue influence.

Witness: _____

Address: _____ City: _____ State _____ Zip Code: _____

Phone: _____

Witness: _____

Address: _____ City: _____ State _____ Zip Code: _____

Phone: _____

FLORIDA DESIGNATION OF HEALTH CARE SURROGATE

Name of Principal: _____

In the event that I have been determined to be incapacitated to provide informed consent for medical treatment and surgical and diagnostic procedures, I wish to designate as my surrogate for health care decisions:

Name: _____ Phone: _____

Street Address City State Zip

If my surrogate is unwilling or unable to perform his duties, I wish to designate as my alternate surrogate:

Name: _____ Phone: _____

Street Address City State Zip

I fully understand that this designation will permit my designee to make health care decisions and to provide, withhold, or withdraw consent on my behalf; to apply for public benefits to defray the cost of health care; to authorize my admission to or transfer from a health care facility, or voluntary admission to a mental health facility; authorize abortion, sterilization and experimental treatments that have not been recommended by a federally approved institutional review board; and authorize withholding or withdrawing life-prolonging procedures (Delete inapplicable or undesired authority, if any). I further affirm that this designation is not being made as a condition of treatment or admission to a health care facility. I will notify and send a copy of this document to the following persons other than my surrogate, so they may know who my surrogate is: (list)

Principle_____
Date

Witness [Neither witness can be designate surrogate. One of the witnesses must be unrelated (by blood or marriage) to Principal.]:

Witness_____
Witness

FLORIDA PROXY'S STATEMENT FOR PATIENT WHO HAS NOT EXECUTED LIVING WILL, SURROGATE DESIGNATION, OR DURABLE POWER OF ATTORNEY

I, _____, am the proxy for _____. I have been appointed as the top ranking person(s) available from the list below (check applicable description):

- ☐ Judicially appointed plenary guardian (if one has been appointed) of the person of the patient;
- ☐ The patient's spouse;
- ☐ An adult child of the patient, or if the patient has more than one child, a majority of the adult children who are reasonably available for consultation;
- ☐ Parent(s) of the patient;
- ☐ The adult sibling of the patient or, if the patient has more than one sibling, a majority of the adult siblings who are reasonably available for consultation;
- ☐ An adult relative of the patient who has exhibited special care and concern for the patient, has maintained regular contact with the patient and is familiar with the patient's activities, health, and religious or moral beliefs; or
- ☐ A close personal friend of the patient who:
 - Is at least eighteen years of age;
 - Has exhibited special care and concern for the patient; and
 - Presents an affidavit that he/she
 - Is a friend of the patient
 - Is willing and able to become involved in the patient's health care; and
 - Has maintained such regular contact with the patient as to be familiar with the patient's activities, health and religious or moral beliefs.
- ☐ A clinical social worker licensed pursuant to Chapter 491 or who is a graduate of a court-approved guardianship program who:
 - Is selected by the providers' bioethics committee and not employed by the provider
 - If the provider does not have a bioethics committee:
 - The proxy may be chosen through an arrangement with the bioethics committee of another provider;
 - A second physician not involved in the patient's care will be available upon request, to assist the proxy in evaluating treatment.
 - Decisions to withhold or withdraw life-prolonging procedures will be reviewed by the provider's bioethics committee.

It is my belief that, based upon clear and convincing evidence, that _____ would want life-prolonging procedures to be withheld or withdrawn under the circumstances. Facts which serve as the clear and convincing evidence upon which this belief is based are as follows (list statements or acts by patient serving as evidence of patient's wishes):

**FLORIDA PROXY'S STATEMENT FOR PATIENT WHO HAS NOT EXECUTED LIVING
WILL, SURROGATE DESIGNATION, OR DURABLE POWER OF ATTORNEY**

I have been informed by the patient's attending physician and another consulting physician and am satisfied that the patient does not have a reasonable probability of recovering competence (so that he/she could express his/her wishes) and that the patient's condition is terminal, is an end stage condition or is a persistent vegetative state. It is further my belief that any limitations or conditions on withholding/withdrawing life prolonging procedures expressed by the patient have been carefully considered and satisfied.

I request that all life-prolonging treatments and procedures be withheld/withdrawn from the patient, and that the patient be allowed to die naturally. I, on behalf of the patient, his/her heirs and estate, hereby release Covenant Hospice, Inc., its employees and agents, and any physician(s) or other healthcare practitioner(s) or provider(s) attending the patient from any and all liability, damages or cause(s) of action for honoring this request that life-prolonging procedures be withheld/withdrawn from the patient. I, on behalf of the patient, his/her heirs and estate, agree to indemnify and hold harmless any and all of the aforementioned healthcare providers for any legal action, including costs of defense, for their compliance with my request on behalf of the patient.

NAMED PROXY

WITNESS

DATE

WITNESS

DATE



State of Florida

DO NOT RESUSCITATE ORDER

(please use ink)

Hospice Number: _____

Patient's Full Legal Name: _____ Date: _____
(Print or Type Name)

PATIENT'S STATEMENT

Based upon informed consent, I, the undersigned, hereby direct that CPR be withheld or withdrawn.

(If not signed by patient, check applicable box):

- | | |
|---|--|
| <input type="checkbox"/> Surrogate | <input type="checkbox"/> Proxy (both as defined in Chapter 765, F.S.) |
| <input type="checkbox"/> Court appointed guardian | <input type="checkbox"/> Durable power of attorney (pursuant to Chapter 709, F.S.) |

(Applicable Signature)

(Print or Type Name)

PHYSICIAN'S STATEMENT

I, the undersigned, a physician licensed pursuant to Chapter 458 or 459, F.S., am the physician of the patient named above. I hereby direct the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation) from the patient in the event of the patient's cardiac or respiratory arrest.

_____ (Signature of Physician)	_____ (Date)	(___) ___ - ____ Telephone Number (Emergency)
-----------------------------------	-----------------	--

(Print or Type Name)

(Physician's Medical License Number)

PHYSICIAN'S STATEMENT

I, the undersigned, a physician licensed pursuant to Chapter 458 or 459, F.S., am the physician of the patient named above. I hereby direct the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation) from the patient in the event of the patient's cardiac or respiratory arrest.

_____ (Signature of Physician)	_____ (Date)	(___) ___ - ____ Telephone Number (Emergency)
-----------------------------------	-----------------	--

(Print or Type Name)

(Physician's Medical License Number)



State of Florida

DO NOT RESUSCITATE ORDER

Patient's Full Legal Name (Print or Type) (Date)

PATIENT'S STATEMENT

Based upon informed consent, I, the undersigned, hereby direct that CPR be withheld or withdrawn.

(If not signed by patient, check applicable box):

- | |
|--|
| <input type="checkbox"/> Surrogate |
| <input type="checkbox"/> Proxy (both as defined in Chapter 765, F.S.) |
| <input type="checkbox"/> Court appointed guardian |
| <input type="checkbox"/> Durable power of attorney (pursuant to Chapter 709, F.S.) |

(Applicable Signature)

(Print or Type Name)

ALABAMA ADVANCE DIRECTIVE FOR HEALTH CARE
(Living Will and Health Care Proxy)

This form may be used in the State of Alabama to make your wishes known about what medical treatment or other care you **would** or **would not** want if you become too sick to speak for yourself. You are not required to have an advance directive. If you do have an advance directive, be sure that your doctor, family, and friends know you have one and know where it is located.

Section 1. Living Will
(Only patient can fill out)

I, _____, being of sound mind and at least 19 years old, would like to make the following wishes known. I direct that my family, my doctors and health care workers, and all others follow the directions I am writing down. I know that at any time I can change my mind about these directions by tearing up this form and writing a new one. I can also do away with these directions by tearing them up and telling someone at least 19 years of age of my wishes and asking him or her to write them down.

I understand that these directions will only be used if I am not able to speak for myself.

If I become terminally ill or injured:

Terminally ill or injured is when my doctor and another doctor decide that I have a condition that cannot be cured and that I will likely die in the near future from this condition.

Life sustaining treatment – Life sustaining treatment includes drugs, machines, or medical procedures that would keep me alive but would not cure me. I know that even if I choose not to have life sustaining treatment, I will still get medicines and treatments that ease my pain and keep me comfortable.

Place your initials by either “yes” or “no”:

I want to have life sustaining treatment if I am terminally ill or injured. ____ Yes ____ No

Artificially provided food and hydration (food and water through a tube or an IV) – I understand that if I am terminally ill or injured I may need to be given food and water through a tube or an IV to keep me alive if I can no longer chew or swallow on my own or with someone helping me.

Place your initials by either “yes” or “no”:

I want to have food and water provided through a tube or an IV if I am terminally ill or injured.
____ Yes ____ No

If I become permanently unconscious:

Permanent unconsciousness is when my doctor and another doctor agree that within a reasonable degree of medical certainty I can no longer think, feel anything, knowingly move, or be aware of being alive. They believe this condition will last indefinitely without hope for improvement and have watched me long enough to make that decision. I understand that at least one of these doctors must be qualified to make such a diagnosis.

Life sustaining treatment - Life sustaining treatment includes drugs, machines, or medical procedures that would keep me alive but would not cure me. I know that even if I choose not to have life sustaining treatment, I will still get medicines and treatments that ease my pain and keep me comfortable.

Place your initials by either "yes" or "no":

I want to have life sustaining treatment if I am permanently unconsciousness. ____ Yes ____ No

Artificially provided food and hydration (food and water through a tube or an IV) – I understand that if I am terminally ill or injured I may need to be given food and water through a tube or an IV to keep me alive if I can no longer chew or swallow on my own or with someone helping me.

Place your initials by either "yes" or "no":

I want to have food and water provided through a tube or an IV if I am permanently unconsciousness. ____ Yes ____ No

Other directions: Please list any other things you want **done** or **not done**.

In addition to the directions I have listed on this form, I also want the following:

If you do not have other directions, place your initials here:

____ No, I do not have any other directions.

**Section 2. If I need someone to speak for me.
(Only patient can fill out)**

This form can be used in the State of Alabama to name a person you would like to make medical or other decisions for you if you become too sick to speak for yourself. This person is called a health care proxy. You do not have to name a health care proxy. The directions in this form will be followed even if you do not name a health care proxy.

Place your initials by only one answer:

_____ I do not want to name a health care proxy. *(If you check this answer, go to Section 3).*

_____ I do want the person listed below to be my health care proxy. I have talked with this person about my wishes.

First choice for proxy: _____

Relationship to me: _____

Address: _____

City: _____ State _____ Zip _____

Day-time phone number: _____

Night-time phone number: _____

If this person is not able, not willing, or not available to be my health care proxy, this is my next choice:

Second choice for proxy: _____

Relationship to me: _____

Address: _____

City: _____ State _____ Zip _____

Day-time phone number: _____

Night-time phone number: _____

Instructions for Proxy

Place your initials by either “yes” or “no”:

I want my health care proxy to make decisions about whether to give me food and water through a tube or an IV if I am permanently unconscious. ____ Yes ____ No

Place your initials by either “yes” or “no”:

____ I want my health care proxy to follow **only** the directions as listed on this form.

____ I want my health care proxy to follow my directions as listed on this form **and** to make any decisions about things I have not covered in the form.

____ I want my health care proxy to make the final decision, even though it could mean doing something different from what I have listed on this form.

Section 3. The things listed on this form are what I want. (Only patient can fill out)

I understand the following:

- If my doctor or other healthcare provider does not follow the directions I have listed, they must see that I get to a doctor or other healthcare provider who will follow my directions.
- If I am pregnant, or if I become pregnant, the choices I have made on this form will not be followed until after the birth of the baby.
- If the time comes for me to stop receiving life sustaining treatment or food and water through a tube or an IV, I direct that my doctor talk about the good and bad points of doing this, along with my wishes, with my health care proxy, if I have one, and with the following people:

Section 4. My signature

Your name: _____

The month, day, and year of your birth: _____

Your signature: _____

Date signed: _____

Section 5. Witnesses (need two witnesses to sign)

I am witnessing this form because I believe this person to be of sound mind. I did not sign the person's signature, and I am not the health care proxy. I am not related to the person by blood, adoption, or marriage and not entitled to any part of his or her estate. I am at least 19 years of age and am not directly responsible for paying for his or her medical care.

Name of first witness: _____

Signature: _____

Date: _____

Name of second witness: _____

Signature: _____

Date: _____

Section 6. Signature of Proxy

I, _____, am willing to serve as the health care proxy.

Signature: _____ Date: _____

Signature of second choice for Proxy:

I, _____, am willing to serve as the health care proxy
if the first choice cannot serve.

Signature: _____ Date: _____

APPENDIX II

**Alabama Portable Physician Do Not Attempt Resuscitation Order
No CPR/ Allow Natural Death**

Patient/Resident Full Name (PRINT) and Date of Birth:

Instructions. This order is valid only if Section I, II, III, OR IV is completed AND a physician has completed Section V.

Section I. Patient/Resident Consent.

I, the undersigned patient/resident, direct that resuscitative measures be withheld from me in the event of cardiopulmonary cessation. I have discussed this decision with my physician, and I understand the consequences of this decision.

Signature of Patient/Resident

Date

Section II. Incompetent Patient/Resident with DNAR instructions in Advance Directive.

The patient/resident is not competent or is no longer able to understand, appreciate, and direct his/her medical treatment and has no hope of regaining that ability. A duly executed Advance Directive for Health Care with instructions that no life sustaining treatment be provided was previously authorized by the patient/resident and is part of his/her medical record.

Signature of provider or facility representative

Print Name

Date

Section III. Health Care Proxy or Attorney-in-Fact Consent.

I, the undersigned, am the health care proxy or attorney-in-fact designated by the patient/resident to make decisions regarding the providing, withholding, or withdrawal of life-sustaining treatment for the patient/resident. I hereby direct that resuscitative measures be withheld from the patient/resident in the event of cardiopulmonary cessation. A copy of the proxy or attorney-in-fact designation (e.g., living will, power of attorney, etc.) has been made part of the patient/resident's medical record.

Signature of Proxy or Attorney-in-Fact

Print Name

Date

Section IV. Surrogate Consent.

I, the undersigned, am the surrogate certified to make decisions, in consultation with the attending physician, regarding the providing, withholding, or withdrawal of life-sustaining treatment for the patient/resident. After consultation with the attending physician, I hereby direct that resuscitative measures be withheld from the patient/resident in the event of cardiopulmonary cessation. I believe that this decision conforms as closely as possible to what the patient/resident would have wanted. I make this decision in good faith and without consideration of the financial benefit or burden which may accrue to me or to the health care provider as a result of this decision. A copy of the Certification of Health Care Decision Surrogate has been made part of the patient/resident's medical record.

Signature of Surrogate

Print Name

Date**Section V. Physician Authorization.**

Based on the information above, I hereby direct any and all medical personnel, emergency responders, and paramedical personnel to withhold resuscitative measures, i.e., cardiopulmonary resuscitation, chest compression, endotracheal intubation and other advanced airway management, artificial ventilation, cardiac resuscitative medications, and cardiac defibrillation, in the event of cardiopulmonary cessation in the patient/resident.

I further direct the implementation of all reasonable comfort care such as oxygen, suction, control of bleeding, administration of pain medication by personnel so authorized, and other therapies to provide comfort and alleviate suffering by the patient/resident; and to provide support to the patient, family members, friends, and others present.

Signature of Physician

Print Name

Date

AUTHORIZATION FOR COVENANT HOSPICE, INC. TO RELEASE INFORMATION

This Authorization applies to any protected health information governed and protected under the Health Insurance Portability and Accounting Act of 1996 (HIPAA), as amended, and under the rules and regulations thereunder. I, the undersigned patient or legally authorized representative, hereby authorize Covenant Hospice, Inc. to use, review, give, disclose and release the health, medical, and mental health information and related records related to my diagnosis, care and treatment, as specified below, to the recipient(s) identified below.

Patient whose information is to be released:

Date of Birth: ____/____/____ Social Security #: _____ Hospice #: _____

Name: _____

Type of information Covenant Hospice, Inc. may release:

- ☐ All of my protected information (including all personal, health, demographics, billing and medical records); OR
- ☐ Only my claims and billing information; OR
- ☐ Other (describe) _____
(Example: Information regarding a specific date of service)

What is the purpose of this Authorization?

- ☐ At my request.
- ☐ Other (explain): _____

I authorize Covenant Hospice, Inc. to release the records identified above to the following person or entity:

Name of Representative

In addition to the authorization and other provisions contained above, I hereby authorize Covenant Hospice, Inc. to use, review, give, disclose and release the following information and records related to my:

- ☐ Mental/behavioral health
- ☐ Psychological/psychiatric evaluations (excluding therapy notes)
- ☐ Neuro-psychological/psychological testing (not including raw data or psychotherapy notes)
- ☐ Alcohol, drug and/or substance abuse information (I understand that my chemical dependency records are protected under federal regulations and cannot be disclosed without my written consent unless otherwise provided for in the regulations)
- ☐ HIV/AIDS related information (including HIV/AIDS testing)
- ☐ Communicable diseases or infections (including venereal disease, tuberculosis, hepatitis, etc.)
- ☐ Physical or sexual abuse information
- ☐ Genetic information
- ☐ Other: _____

AUTHORIZATION FOR COVENANT HOSPICE, INC. TO RELEASE INFORMATION

Hospice # _____

Acknowledgement:

I understand that I may refuse to sign this Authorization. I understand that I may revoke this Authorization at any time, except to the extent that action has already been taken in reliance upon it, by giving written notice to Covenant Hospice. I have the right to receive a copy of this Authorization after I sign it. I have the right to inspect or request a copy of the protected health information to be used, released or disclosed. I understand that Covenant Hospice may not condition treatment, payment, enrollment or eligibility benefits on whether or not I sign the Authorization. My personal and health information, once it is released, may be re-disclosed by the recipient without my knowledge or consent, and if re-disclosed, the information would no longer be protected by law. A copy of this Authorization (including a fax copy, photocopy or e-mail) may be used with the same effectiveness as the original.

Any facsimile, copy or photocopy of this Authorization shall authorize you to release the records requested herein. This Authorization shall be in force and effect until two (2) years from date of execution at which time this Authorization expires.

Signature of Patient or Legally Authorized Representative

Date

Print Name and Relationship of Legally Authorized Representative to Patient

Address

City, State, Zip Code

Witness Signature

Date

***Note: "Legally Authorized Representative" means Proxy, Surrogate, Power of Attorney, Legal Guardian or Parent of Minor Child.**

AUTHORIZATION FOR RELEASE OF CONFIDENTIAL INFORMATION TO COVENANT HOSPICE, INC.

Patient's Name: _____

Hospice # _____

Date of Birth: ____ / ____ / ____

Social Security # _____

I hereby authorize **any and all Medical Providers**, including, without limitation, _____ to disclose the following information regarding my individually identifiable health information contained in my records to:

Covenant Hospice, Inc. located at 5041 N. 12th Avenue, Pensacola, Florida 32504, for the purpose of:

Specific purpose for disclosure of records

Information to be disclosed may include: (Please check all applicable):

____ History and Physical Examination

____ ER and/or OPS

____ X-Ray Reports

____ Discharge Summary

____ Doctor's Progress Notes/Order

____ Laboratory Tests

____ Consultations

____ Operative Reports

____ Pathology Reports

____ Billing Records

____ Other (please specify): _____

In addition to the authorization and other provisions contained above, I hereby authorize Covenant Hospice, Inc. to use, review, give, disclose and release the following information and records related to my:

- ☐ Mental/behavioral health
- ☐ Psychological/psychiatric evaluations (excluding therapy notes)
- ☐ Neuro-psychological/psychological testing (not including raw data or psychotherapy notes)
- ☐ Alcohol, drug and/or substance abuse information (I understand that my chemical dependency records are protected under federal regulations and cannot be disclosed without my written consent unless otherwise provided for in the regulations)
- ☐ HIV/AIDS related information (including HIV/AIDS testing)
- ☐ Communicable diseases or infections (including venereal disease, tuberculosis, hepatitis, etc.)
- ☐ Physical or sexual abuse information
- ☐ Genetic information
- ☐ Other: _____

Acknowledgement

1. By signing this Authorization, I authorize Covenant Hospice, Inc. to obtain, use and/or disclose my health information in the manner described above. I understand that I am under no obligation to sign this Authorization and that conditions of treatment, payment or enrollment in a health plan or eligibility for health care benefits cannot be based upon my decision to sign this Authorization.
2. I understand I have the right to revoke this Authorization at any time and will do so in writing to Covenant Hospice, Inc. except to the extent that action by Covenant Hospice, Inc. has been taken in reliance on this Authorization.

AUTHORIZATION FOR RELEASE OF CONFIDENTIAL INFORMATION TO COVENANT HOSPICE, INC.

Hospice # _____

Any facsimile, copy or photocopy of this Authorization shall authorize you to release the records requested herein. This Authorization shall be in force and effect until two (2) years from date of execution at which time this Authorization expires.

Signature of Patient or Legally Authorized Representative

Date

Name and Relationship of Legally Authorized Representative to Patient

Address

City, State, Zip Code

Witness Signature

Date

****Note: "Legally Authorized Representative" means Proxy, Surrogate, Power of Attorney, Legal Guardian or Parent of Minor Child.***

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One wish
changes everything.

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How it works

- Your Covenant Care team will help you and your family identify a wish that will create lasting memories.
- Our Wish Team will swing into action and make every effort to grant your My Wish.

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FOR MORE INFORMATION

Call **888-LUV-2WISH**

Email **wish@MyWish.org**

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covenant care

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