



Patient and Family Resource Guide

Updated January 2023

QUICK REFERENCE

Your Tidewell Hospice team is here to answer your questions 24/7. From 8 am-5 pm call the office closest to your location listed below:

Office Location	Office Number
[] Arcadia	(863) 231-3300
[] Bradenton	(941) 782-4900
[] Ellenton	(941) 845-3000
[] Englewood	(941) 548-2300
[] Port Charlotte	(941) 979-4300
[] Sarasota	(941) 487-3100
[] Venice	(941) 441-2000

For after hours, weekend or on holidays, call toll free (855) 843-3935. For more information about admission to Tidewell, call our Care Navigation Center at (941) 894-1777.

Physician: _____

Clinical Director: _____

Nurse: _____

Social Worker: _____

CNA: _____

Chaplain: _____

Volunteer: _____

This guide accompanies the patient wherever he or she is receiving care.

Tidewell’s “Let Me Teach You” guides offer easy, step-by-step training for providing daily care for your family member. Visit TidewellHospice.org/Let-Me-Teach-You.

OUR MISSION

*United in empathy, we serve our communities
through extraordinary Full Life Care for all.*

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FROM EMPATH HEALTH'S CEO TO YOU—



For more than 40 years, your local not-for-profit Tidewell Hospice, a member of Empath Health, has been honored to offer compassionate, caring service in our community. On behalf of everyone at Tidewell, I want to thank you for choosing us to assist with the care of your loved one.

We realize that this is a significant time in your life and you probably have many questions. To help you and your family learn about what to expect, we have designed this special guide. It provides information that allows you to better understand the physical changes illness may bring, and also serves as a guide for managing those changes as a caregiver. As you read this book and interact with our staff, we encourage you to ask questions. Knowing what to expect usually makes everyone more confident and better able to communicate at each step along the journey.

Tidewell takes a team approach to care that includes the patient, loved ones, the primary-care physician, nurses, social workers, pharmacists, personal care aides, chaplains and volunteers. A nurse visits regularly to help manage individual needs. The nurse and certified nursing assistant teach you how to perform simple caregiver tasks easily. In addition to helping with emotional concerns, your social worker can provide information about legal issues and lead you to extensive community resources that may be helpful in your particular situation.

The staff and volunteers of Tidewell can teach you many skills. These skills, combined with your love and commitment, ensure the very best care. We strive to meet the physical, emotional and spiritual needs of your loved one, enabling you to do and say the things that mean the most and fulfill important wishes.

If you have any questions or need additional information, please feel free to ask your team members or call the telephone number at the front of this guide. It is very important to us that you feel confident that support and care are available to you any time, day and night.

We are honored and privileged to serve you, your loved one and family. Thank you again for choosing Tidewell.

A handwritten signature in black ink that reads "Jonathan D. Fleece".

Jonathan Fleece
President & CEO, Empath Health & Its Affiliates

OUR PROGRAMS

Tidewell Hospice, a member of Empath Health, is a nonprofit providing a full range of hospice services to patients with advanced illness and their families throughout Manatee, Sarasota, Charlotte and DeSoto counties. Compassionate care and quality-of-life programs are available to anyone with advanced illness who needs and wants hospice care — regardless of age, gender, ethnicity, diagnosis, belief system or financial situation. Many of our programs are free of cost, thanks to the generous funding by donors to our Tidewell Foundation.

TIDEWELL HOSPICE

- Diagnosis of advanced illness with prognosis of six months or less.
- Seeking comfort care, relief of pain and symptoms.
- Support for patient and family wherever the patient resides.
- Multidisciplinary team: physician, nurse, social worker, pharmacist, chaplain, certified nursing assistant and volunteer.
- Expert care for people with advanced illness addresses physical, emotional, psychosocial and spiritual needs of patient and family.
- Medicare/Medicaid, private pay and private insurance accepted. Care provided to all regardless of ability to pay.

PALLIATIVE CARE

- Collaboration between Tidewell Hospice, Empath Medical Services and community healthcare professionals to provide palliative care.
- Have a diagnosis of an advanced, progressive illness.
- Whole person/family care directed at improving quality of life and achieving patient/family goals.
- Can be combined with therapies to promote life prolongation.
- Focuses on comfort, pain and symptom management and enhanced quality of life.

EMPATH HOME HEALTH

- Licensed Medicare services including skilled nursing, physical therapy, occupational therapy and speech therapy.

EMPATH PERSONAL CARE

- Provides personal care assistance with bathing, shaving, hair and skin care, dental hygiene, morning and evening routines, dressing, incontinent care, transferring in and out of bed.
- Offers socialization, scheduling of medical/non-medical appointments and other scheduling, transport to a doctor's appointment or pharmacy, shopping and running errands, ensures medications are taken safely and on time, offers respite for family members.
- Provides homemaking services such as preparing nourishing meals, cleaning bathrooms and kitchen, vacuuming and dusting, taking out the trash, washing and ironing, changing linens.

CHILDREN'S SERVICES

- Hospice for patients under 21 years of age with advanced illness.
- Developmentally-appropriate pain and symptom management, emotional, spiritual and grief support.
- Interdisciplinary approach of pediatric experts in nursing, counseling and grief support.
- Care is provided in the child's home when appropriate.
- 24-hour-a-day, seven-day-a-week availability.
- Art, music and play therapies to help children and families express feelings and learn coping skills.

PARTNERS IN CARE (PIC)

- In partnership with Children's Medical Services (CMS), this is a Medicaid waiver program for children with advanced illness.
- Admission criteria include enrollment in CMS and certification by a physician.
- Tidewell care teams work with primary medical team, family, school and day care to ensure continuity of care.

GRIEF EDUCATION AND SUPPORT CENTER

- Grief support provided for anyone in the community following the death of a loved one.
- Grief counseling in one-on-one and group settings.
- Specialty support groups in the community, such as Survivors of Suicide (SOS).
- Grief support provided to children and teens who have lost a loved one.
- All of our grief services are free of charge thanks to the support of generous donors to the Tidewell Foundation.

INFORMATION ONLINE

At TidewellHospice.org/Patient-Family-Resources you will find video and other educational resources addressing end-of-life care.

Please feel free to share this link with other family members and friends who may be involved with providing care to your loved one.

GETTING STARTED WITH TIDEWELL

Referrals may come from any of the following:

- Doctor
- Nurse
- Social worker
- Family or friend
- Patient
- Clergy

To start the Tidewell admission process, call (941) 894-1777

Where is care provided?

- In a private home
- Group home
- Nursing facility
- Tidewell Hospice House
- Hospital
- Assisted-living facility
- Anywhere the person lives

Do patients keep their own doctor?

Yes, Tidewell Hospice works directly with the patient's doctor or Tidewell's physicians can provide care. The choice is yours.

What happens if the patient moves out of the area?

Tidewell can assist with the transition to a hospice in the area to which you are relocating.

What happens if we no longer want or need Tidewell's services?

Patients always have the choice to discontinue services by signing a revocation form. If a patient's condition stabilizes, the Tidewell team will discuss discharge with the patient and family. If you notice changes in the patient's condition, call us. Tidewell services will always be available when needed.

We value your opinion.

During and after your loved one receives hospice care with Tidewell, you may be asked about your level of satisfaction with our services. We appreciate your honest feedback. It is the best way for us to measure the quality of our programs and uncover areas for improvement.

PERSONAL INFORMATION AND RECORDS

General recommendations:

1. Make a list of the loved one's assets.
2. Make copies of all important documents. Keep the originals in a safe, fire proof, locked place.
3. Make sure there is more than one key and that the family knows where the key is kept.
4. Label any other keys for the benefit of those handling affairs later on.
5. Refer questions regarding the loved one's estate to an attorney.

PERSONAL INFORMATION AND RECORDS CHECKLIST

Living Will ☐ yes ☐ no

Location: _____

Durable Power of Attorney for Healthcare ☐ yes ☐ no

Location: _____

General Durable Power of Attorney ☐ yes ☐ no

Location: _____

Attorney

Name: _____

Address: _____

Phone: _____

Will

Location of will: _____

Executor of will: _____

If your loved one does not have a will, the first priority is to prepare one. If he or she does have a will, this is a good time to review the information.

Insurance Policies and Policy Numbers

Life insurance (group and/or individual): _____

Health insurance: _____

Auto insurance: _____

Disability insurance: _____

Renter's/Homeowner's insurance: _____

Insurance Agent/Broker

Name: _____

Address: _____

Phone: _____

Real Estate Deeds

Location of property: _____

Titles in name(s) of: _____

Mortgages, Records or Mortgage Payments Information

Brokerage Firm/Broker

Name:

Address:

Phone:

Savings/Credit Union Account

Held at:

Acct.#

Checking Account

Held at:

Acct.#

Safe Deposit Box

Box Number:

Location of box and key:

Name box is under:

City, State, Federal Tax Returns (past several years)

Location:

Birth Certificate

Location: _____

Social Security Card

Location: _____

Marriage/Divorce Certificate

Location: _____

Automobile Titles

Location: _____

When your loved one is no longer able to drive, a transfer of title and change in primary insured is recommended.

Military Discharge Papers

Location: _____

Contracts (installment purchase agreements, service contracts)

Location: _____

HEALTHCARE ADVANCE DIRECTIVES

The Patient's Right to Decide

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

When a person becomes unable to make decisions due to a physical or mental change, such as being in a coma or developing dementia (like Alzheimer's disease), he or she is considered incapacitated. To make sure that an incapacitated person's decisions about healthcare will still be respected, the Florida legislature enacted legislation pertaining to healthcare advance directives (Chapter 765, Florida Statutes). The law recognizes the right of a competent adult to make an advance directive instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures; to designate another individual to make treatment decisions if the person becomes unable to make his or her own decisions; and/or to indicate the desire to make an anatomical donation after death.

By law, hospitals, nursing homes, home health agencies, hospices and health maintenance organizations (HMOs) are required to provide their patients with written information concerning healthcare advance directives. The state rules that require this include 58A-2.0232, 59A-3.254, 59A-4.1 06, 59A-8.0245, and 59A-12.013, Florida Administrative Code.

Tidewell Hospice does not require that patients have a healthcare advance directive or a do not resuscitate order (DNRO). In the absence of an advance directive or a designated surrogate decision maker, per FL Statute 765.401, a judicially-appointed guardian or the closest next of kin may act as the proxy decision maker. In the absence of a DNRO, Tidewell Hospice staff can assist in obtaining one. If the patient or surrogate decision maker chooses not to complete a DNRO, 9-1-1 may be called and emergency measures may be initiated if the patient goes into cardiac/respiratory arrest.

QUESTIONS ABOUT HEALTHCARE ADVANCE DIRECTIVES

What is an advance directive?

It is a written or oral statement about how someone wants medical decisions made should he or she not be able to make them and/or it can express wishes to make an anatomical donation after death. Some people make advance directives when they are diagnosed with a life-threatening illness. Others put their wishes in writing while they are healthy, often as part of their estate planning.

Examples of advance directives are:

- Living will
- Healthcare surrogate designation
- An anatomical donation
- Do not resuscitate

Someone might choose to complete one or more of these advance directives.

What is a living will?

It is a written or oral statement of the kind of medical care a person wants or does not want if he or she becomes unable to make his or her own decisions. It is called a living will because it takes effect while the person is still living. A patient may wish to speak to a healthcare provider or attorney to be certain he or she has completed the living will in a way that the wishes will be understood.

What is a healthcare surrogate designation?

It is a document naming another person as the representative to make medical decisions for someone if he or she is unable to make them. The document can include instructions about any treatment the person wants or does not want, similar to a living will. It can also designate an alternate surrogate.

Which is best?

Depending on the individual's needs, he or she may wish to complete one or more of the types of advance directives.

What is a do not resuscitate order (DNRO)?

A DNRO identifies people who do not wish to be resuscitated from respiratory or cardiac arrest. The prehospital DNRO is a specific yellow form available from the Florida Department of Health (DOH).

What is an anatomical donation?

It is a document that indicates a person's wish to donate, at death, all or part of his or her body. This can be an organ and tissue donation to persons in need or donation of the body for training of healthcare workers. The person can indicate his or her choice to be an organ donor by designating it on a driver's license or state identification card, signing a uniform donor form or expressing a wish in a living will.

Is a person required to have an advance directive under Florida law?

No, there is no legal requirement to complete an advance directive. However, if a person has not made an advance directive, decisions about healthcare or an anatomical donation may be made by a court-appointed guardian, the spouse, adult child, parent, adult sibling, adult relative or a close friend.

The person making decisions may or may not be aware of the person's wishes. Advance directives should be discussed with the significant people in a person's life to make sure the wishes are carried out as the person wants.

Must an attorney prepare the advance directive?

Advance directive procedures are simple and do not require an attorney, though a person may choose to consult one.

However, an advance directive, whether it is a written document or an oral statement, needs to be witnessed by two individuals. At least one of the witnesses cannot be a spouse or a blood relative.

Where are advance directive forms found?

Florida law provides a sample of each of the following forms: a living will, a healthcare surrogate, and an anatomical donation.

Can advance directives be changed?

Yes, a person may change or cancel an advance directive at any time. Any changes should be written, signed and dated. However, an advance directive can also be changed by oral statement; physical destruction of the advance directive; or by writing a new advance directive.

If a person changes his or her mind about being an organ donor, his or her driver's license or state identification can be revised by contacting the nearest driver's license office to cancel the donor designation, and a new license or card will be issued.

Are advance directives from another state valid in Florida?

An advance directive completed in another state, as described in that state's law, can be honored in Florida.

What should be done with an advance directive?

If the directive designates a healthcare surrogate and an alternate surrogate, be sure to ask them if they agree to take this responsibility; discuss how matters should be handled and give them a copy of the document.

Make sure that the healthcare provider, attorney and the significant people in the person's life know that he or she has an advance directive and where it is located and perhaps give them a copy.

Set up a file for keeping a copy of the advance directive (and other important paperwork). Original papers may be kept in a bank safety deposit box, but keep copies at the person's residence or share the location of the safety deposit box.

If the advance directive is changed, make sure the healthcare provider, attorney and the significant people have the latest copy.

Questions about advance directives can be discussed with a healthcare provider, attorney or the significant people in the person's life.

More Information on Healthcare Advance Directives

Before making a decision about advance directives, your loved one might want to consider additional options and other sources of information including the following:

- As an alternative to a healthcare surrogate, or in addition to, he or she might want to designate a durable power of attorney. Through a written document, your loved one can name another person to act on his or her behalf. It is similar to a healthcare surrogate, but the person can be designated to perform a variety of activities (financial, legal, medical, etc.). Please consult an attorney for further information or read Chapter 709, Florida Statutes.
- If someone is chosen as durable power of attorney, be sure that person has agreed to take this responsibility. That person should know how your loved one would like matters handled and have a copy of the document.
- A person who is terminally ill or is in a persistent vegetative state may want to consider having a prehospital Do Not Resuscitate Order (DNRO). An attorney, healthcare provider or an ambulance service may have copies of a DNRO available. A legal representative and physician sign the DNRO form. More information is available at DOH.State.FI.us or MyFlorida.com (type DNRO in these website search engines) or call (850) 245-4440.

- When a person is admitted to a hospital, the prehospital DNRO may be used or the hospital may have its own form and procedure for documenting a Do Not Resuscitate Order.

My Life, My Choice is a free advance care planning program for adults. Visit EmpathHealth.org/MyLifeMyChoice for more information.

- If a person chooses to donate his or her body for medical training and research, the donation will be coordinated by the Anatomical Board of the State of Florida. The person's survivors must make arrangements with a local funeral home and pay for a preliminary embalming and transportation of the body to the Anatomical Board located in Gainesville. After being used for medical education or research, the body is usually cremated. The cremains are returned to the loved ones if requested at the time of donation, or the Anatomical Board will spread the cremains over the Gulf of Mexico. For further information contact the Anatomical Board of the State of Florida at (800) 628-2594 or Med.ufl.edu/Anatbd.
- More information about organ and tissue donation can be found on the Agency for Healthcare Administration's website AHCA.MyFlorida.com (Click on "Site Map" then scroll down to "Organ Donors") or the federal government site OrganDonor.gov. A healthcare provider can answer additional questions.
- Various organizations also make advance directive forms available, including BegintheConversation.org, [Five Wishes](https://FiveWishes.org) and [Aging with Dignity](https://AgingWithDignity.org) at AgingWithDignity.org or (888) 594-7437.

Other resources:

- American Association of Retired Persons (AARP), AARP.org (type "advance directives" in the website's search engine.)
- Hospitals, nursing homes, hospice, home health agencies, attorneys or healthcare provider may be able to assist with forms or further information.
- End-of-life Issues brochure, FloridaHealthFinder.gov (888) 419-3456.

THE HOSPICE BENEFIT

MEDICARE HOSPICE BENEFIT

Medicare Part A provides a special program for persons needing hospice care.

These services are delivered to hospice patients — wherever the patient resides — by a Medicare-certified hospice program, like Tidewell. The Medicare Hospice Benefit covers services, medications, supplies and equipment that are related to life-limiting illness.

MEDICAID HOSPICE BENEFIT

Some patients may meet the financial eligibility requirements for reimbursement under Hospice Medicaid. Hospice Medicaid provides the same coverage as defined by the Medicare benefit. A Medicaid card confirms eligibility for this benefit.

PRIVATE INSURANCE BENEFIT

Most private insurances have a hospice benefit. A member of the Tidewell team will discuss how insurance benefits are accessed. In some situations, the hospice benefits provided by insurance companies have individual requirements based on their individual plan definitions. Tidewell works directly with the insurance companies to maximize care and services.

PRIVATE PAY AND UNCOMPENSATED CARE

Hospice services provided that are not covered by Medicare, Medicaid or private insurance reimbursement may be the responsibility of the patient. A member of the Tidewell team will meet with the patient and family to discuss any assessed fees for services prior to admission and upon changes in the plan of care. A sliding fee scale may be used to assess the ability to provide private payment. Tidewell never prevents or interrupts care at any time because of inability to pay. Eligibility for uncompensated care can be discussed with a social worker.

HOW HOSPICE MEDICARE/MEDICAID BENEFITS WORK

Pre-authorization

All healthcare services must be pre-authorized by Tidewell Hospice to be covered under the hospice benefit. If the patient elects to receive medical or hospital services which are not directly provided or authorized by Tidewell Hospice, he or she may either self-pay for that service or revoke the hospice benefit. Medicare pays Tidewell directly at specified daily rates for care provided. Therefore, Tidewell delivers care based on the plan of care and is not responsible for care obtained for the patient outside of this plan of care. Remember, these restrictions apply only to the terminal diagnosis. Unrelated medical problems will be treated through the patient's regular healthcare provider.

Please contact the Tidewell nurse or social worker with any questions or concerns regarding coverage under the hospice benefit.

Who is eligible for this benefit?

- The patient whose doctor has confirmed the terminal diagnosis.
- The patient who signs a statement choosing hospice care benefits.
- The patient who receives care from a Medicare-approved hospice.
- The patient who seeks care focused on comfort and quality of life.

What is a benefit period?

The Medicare Hospice Benefit consists of two, 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of the first 180 days of care, and at the end of each following 60-day period, Tidewell is required to perform a face-to-face visit to determine whether the patient continues to meet the hospice eligibility criteria. An advanced registered nurse practitioner (ARNP) or physician will visit to determine if the patient may or may not continue to be eligible to receive the Medicare Hospice Benefit.

If the patient has improved to the point of no longer meeting the Medicare Hospice Benefit criteria, the Tidewell team will discuss alternatives to hospice care with the patient and family.

What is included in hospice services?

Working together with the patient, his or her physician and Tidewell staff, the scope of the services provided may change based on a current assessment of patient needs. Services may include:

- Physician services
- Case management by a registered nurse (RN)
- Professional nursing
- Personal care
- Homemaker
- Social work counseling/support
- Bereavement support
- Ability to contact Tidewell 24/7
- Patient/family education
- Medications and infusions included in the plan of care (POC)
- Home medical equipment included in the POC
- Medical supplies included in the POC
- Volunteer support
- Chaplain support
- In-home care
- Care in long-term care (LTC) setting
- Care in assisted-living (ALF) setting
- Care in hospital setting
- Children's program
- Respite care
- Short-term crisis care, if service criteria are met
- Short-term symptom control in a hospice house, hospital or specialized long-term care facility, if criteria is met

THE HOSPICE BENEFIT LEVELS OF CARE

These levels of care guide the reimbursement and care for a hospice patient per federal and state regulations. Each care level has different regulations that must be followed to receive that reimbursement. The benefit applies to Medicare and Medicaid recipients.

Routine Home Care

Routine home care is provided if the patient is living in a home environment (ALF, LTC, individual home) and is progressing with an advanced illness. The Medicare Hospice Benefit does not pay for room and board in any facility.

In the nursing home setting, room and board may be paid for through a particular Medicaid program if a patient financially qualifies. Tidewell's social worker is able to explain the qualification requirements.

Short-term Routine Care in Hospice House

Short-term stays in the hospice house are available if the needs of the patient are unable to be met in the current setting. The hospice house team begins working with the patient/family at admission to the hospice house to determine and arrange appropriate discharge planning.

Room and board is not covered by Medicare, Medicaid or private insurance. The patient/family is responsible for the cost of room and board. A financial assessment is done by Tidewell's social worker to determine the patient's ability to pay for the cost of room and board and a sliding fee scale is available to calculate the appropriate amount due. No one is denied care due to inability to pay.

Respite Care

Caregiving can be challenging and stressful. There are times when caregivers need a break. Respite (or rest) care gives the caregiver the opportunity for time off to recharge. Respite care is part of the benefit provided by Medicare, Medicaid and most private insurances.

How is respite obtained?

The patient is placed in a hospice house or a skilled nursing facility where Tidewell Hospice has a contract. Respite care can last up to five days and can occur as approved by the Tidewell team. The setting is different for respite care, but the care does not change. All situations are unique and respite is considered

on a case-by-case basis. If you have questions about the availability of respite care, please consult any of your Tidewell representatives.

How should the patient/caregiver prepare for respite?

Pack the patient's personal items (brush, comb, toothbrush, and so on), as well as any clothing the patient wants. The nurse will advise you if the patient's medications and supplies are to be taken to the receiving facility. This guide should also accompany the patient.

How should the patient get to the facility?

If possible, the family should take and subsequently pick up the patient at respite care. If this isn't possible, transportation needs can be discussed with the Tidewell team.

Crisis Care

Crisis care is the short-term management of acute pain or other symptoms. It is designed to prevent a crisis that may lead to hospitalization and includes at least 8 hours of skilled nursing care provided by Tidewell in a 24-hour period. This care is provided in the patient's home environment, wherever that may be. If it looks as though this type of care might be needed, the Tidewell nurse will discuss the options with you.

General Inpatient Care (GIP)

Short-term care provided in an approved facility involves medical oversight and regular Tidewell staff involvement to address issues of acute pain or other symptoms that cannot be managed well in a home setting. An appropriate plan of care including discharge planning is developed at admission. Admission to GIP must meet prior approval from the Medical Director.

How does the Medicare Hospice Benefit cover hospitalization?

The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the terminal illness, including the emergency room. Remember, **CONTACT TIDEWELL DAY OR NIGHT BEFORE CONSIDERING ANY TYPE OF HOSPITALIZATION.**

How is the doctor paid?

For Medicare patients, the current coverage under Medicare Part B continues to cover the doctor's costs for overseeing the plan of care and any direct medical care provided.

The doctors of patients with other insurances are paid according to the specific plan. The doctor usually knows the details or the Tidewell nurse or social worker can find out the information.

How is transportation paid?

Tidewell can help coordinate transportation and collaborate on any discharge plan of care in order to ensure a good transition to post-discharge care.

Tidewell is financially responsible for transportation if:

- The patient is currently receiving hospice care and the hospital stay is related to hospice diagnosis and requires transport home or to hospice house when discharged from the hospital.
- The patient is being transported to and from doctor appointments, diagnostics and treatments that are part of the hospice plan of care.

Tidewell is NOT financially responsible for transportation if:

- The patient is discharged from a hospital acute-care stay to hospice at home or a hospice house.
- The patient has not been admitted to hospice.
- The patient is admitted to the hospital for reasons unrelated to the hospice diagnosis. Example: The patient is with hospice for lung cancer and is admitted to the hospital for a fractured hip after falling off a step stool.
- The patient is transported to the hospital, to appointments or to other residences if the reason for the trip is not related to the hospice diagnosis. Example: Patient moves from one residence to another or to doctor appointments, diagnostics or treatments unrelated to the hospice plan of care.

INPATIENT ADMISSION FOR SYMPTOM CONTROL

Why is symptom control needed?

When the patient has increased pain, nausea, shortness of breath or some other problem, the Tidewell team may suggest a symptom control admission. The goal of this admission is to relieve or decrease the severity of the symptoms. This type of admission is meant to be short, with the hope of returning the patient home as soon as possible.

Where does the patient go for symptom control?

Usually, the patient is admitted to one of Tidewell's hospice houses or care centers. However, if the patient's physician recommends care at an alternate location it can be arranged by the Tidewell team.

TIDEWELL SERVICES IN FACILITIES

People living in long-term care facilities (nursing homes), assisted-living facilities or group homes may receive hospice care. A team of specialized hospice workers who are familiar with the staff and requirements of these facilities provides the same support and care for residents as it does for someone living in a private home. Tidewell Hospice works collaboratively to coordinate hospice care with the many facilities in its service area.

The hospice care provided by Tidewell enhances the care provided by the facility staff. Supplies, equipment and medications needed as a result of the advanced illness are provided for patients eligible for a hospice benefit through their insurance. The charge for room and board is not covered under the Medicare or Medicaid hospice benefit, but Medicaid does have a program to help with room and board at the facilities for patients who qualify financially.

If the patient lives at home but needs placement in a facility, the Tidewell social worker helps locate a facility that works in collaboration with Tidewell Hospice.

FINANCIAL INFORMATION

THE HOSPICE MEDICARE BENEFIT

The Medicare Hospice Benefit is available to everyone who qualifies for Medicare Part A and has a life expectancy of six months or less if their disease runs its normal course. The hospice benefit is available to all — regardless of where they reside.

As a Medicare-approved hospice provider, Tidewell Hospice is responsible for providing all hospice services under the Medicare Hospice Benefit.

What the Hospice Benefit Covers

Once the patient and family choose hospice care, the hospice benefit should cover everything the patient needs. It is only in rare situations he or she will need to go outside of hospice for care. Medicare covers the hospice care for terminal illness and related conditions, but the care must be provided by a Medicare-approved hospice provider, like Tidewell.

The Medicare Hospice Benefit covers care related only to the terminal illness and related conditions. Care for illnesses and conditions not related to the hospice diagnosis are still covered under the patient's original Medicare coverage, even if he or she was previously enrolled in a Medicare Advantage Plan (like an HMO or PPO) or other Medicare health plan. Premiums, deductibles and coinsurance amounts required by Medicare to treat health problems that aren't part of the hospice diagnosis must still be paid by the patient and family.

Important: Once your loved one chooses hospice care, the Medicare Hospice Benefit should cover everything he or she needs. Original Medicare still pays for covered benefits for any other health problems that aren't part of the terminal illness and related conditions.

Hospice care is usually provided at home, unless the patient needs care in an inpatient facility. If Tidewell determines that the person needs inpatient hospice care, the hospice team makes the arrangements for the stay. Depending on the patient's illness and related conditions, the plan of care the hospice team creates can include any or all of these services:

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Prescription drugs
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for the patient and family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care
- Any other Medicare-covered services needed to manage the terminal illness and related conditions, as recommended by the hospice team

If a patient has Medicare Part A (hospital insurance) **AND** meets these conditions, he or she can get hospice care:

The hospice doctor and patient's doctor certify the patient is terminally ill with a life expectancy of six months or less.

The patient accepts palliative care for comfort instead of care to cure the illness.

The patient signs a statement choosing hospice care instead of other Medicare-covered treatments for the terminal illness and related conditions.

HOSPICE AND MEDICARE ADVANTAGE PLANS OR OTHER MEDICARE HEALTH PLAN

A Medicare Advantage Plan, like an HMO or PPO, is another type of Medicare health plan offered by a private insurance company. The private insurance company has a contract with Medicare to provide Medicare Part A hospital insurance and Medicare Part B medical insurance benefits.

When a patient with a Medicare Advantage Plan or other Medicare health plan chooses hospice care, the hospice services are covered by Original Medicare. The Medicare hospice benefit should cover everything the hospice patient needs. Original Medicare still pays for any health problems that aren't part of the terminal illness and related conditions that make the patient eligible for the hospice benefits (this is very rare).

Medicare-covered services that aren't part of hospice care can be selected through a Medicare Advantage Plan or Original Medicare. If the Medicare Advantage Plan covers additional services not covered by Original Medicare (such as dental and vision benefits), it continues to cover these extra services as long as the premiums are paid.

HOSPICE CARE IN A MEDICAID MANAGED CARE PLAN

Hospice services are covered as part of Medicaid Managed Care Plan benefits. Care is provided by a hospice team that may include the patient, the family, and others who can help meet the physical, psychosocial, spiritual, and emotional needs. Patient needs are written in a plan of care (POC), also called a plan. Below are examples of the hospice services provided:

- Physician services provided by hospice
- Nursing care
- Medical equipment
- Medical supplies
- Drugs for symptom control and pain relief
- Hospice aide and homemaker services
- Physical therapy
- Occupational therapy
- Speech-language pathology services

- Social worker services
- Dietary counseling
- Short-term inpatient care for pain control, symptom management and respite care at a hospice house or long-term care facility

Hospice benefits may also include everything needed to manage the terminal illness and related conditions normally covered by Medicaid. Medicaid also covers room and board in long-term care facilities for patients who meet Medicaid eligibility criteria.

HOSPICE CARE IN PRIVATE INSURANCE PLAN

A patient covered by private medical insurance receives the same hospice services provided under Medicare benefits.

Deductibles and coinsurance required by the private insurance plan must still be paid by the patient and family, as well as any plan premiums. Tidewell sends a statement regarding the amount owed for deductibles and coinsurance and works with you to make arrangements for payment.

SLIDING FEE SCALE

In some situations, a patient or his or her family may be required to pay a portion of the cost of hospice care. A sliding payment system is used to determine those charges, and the Tidewell team members will discuss with you how the fees are calculated if the patient:

1. Does not have any third-party insurance coverage.
2. Applies for Medicaid (Medicaid pending).
3. Resides at the hospice house under the residential level of care.
4. Has private insurance policy with a cap or maximum limit on the hospice benefit to be paid.

PAYMENT FOR MEDICATIONS WHILE IN HOSPICE CARE

The Medicare Hospice Benefit covers payment for all prescribed medications to manage the symptoms of the terminal illness and other related conditions. These medications usually include medicine for pain, anxiety, nausea, constipation and other symptoms related to the terminal illness. These medications are prescribed for the patient by his or her physician and/or the Tidewell physician and are delivered directly to the location where the patient is receiving care. If the medications being prescribed are considered “reasonable and necessary” for the hospice diagnosis and are included in the hospice medication list, called a formulary, the medications are paid for by Tidewell.

A hospice patient may request medication not included in the approved hospice medication list, but if similar covered medications are available the patient is responsible for the cost of the off-list (nonformulary) medication. The only exception is if Tidewell's physician determines that the off-list medication is reasonable and necessary for the patient. Then Tidewell covers the cost of the prescription under the Medicare Hospice Benefit.

Medications not related to the terminal illness and related conditions are not paid for by Tidewell. Medicare Part D or private insurance may cover prescription medications not related to the hospice diagnosis. Please note that Medicare Part D only pays for prescribed medications not related to the hospice terminal illness or related conditions.

IMPORTANT: Please call Tidewell to report:

- Any new medication or changes to a medication regimen prior to having new prescriptions filled.
- Any delays or barriers getting prescriptions under Medicare Part D that are caused by the patient's hospice status.

Prescription Medication Benefit Summary

Tidewell Hospice covers	Prescribed formulary medication reasonable and necessary for the terminal illness and other related conditions.
Tidewell Hospice covers	Prescribed nonformulary medication for symptom relief of terminal illness and other related conditions that a physician has deemed necessary and for which there is not a reasonable formulary option.
Medicare Part D covers	Prescribed medications completely unrelated to the hospice illness and other related conditions for eligible enrolled patients. Medication coverage is subject to Part D Plan formulary, rules and restrictions.
Patient covers	Prescribed medication the patient wishes to continue taking but hospice has deemed not medically necessary or beneficial; nonformulary medication for which there is a reasonable formulary option.

WHAT THE MEDICARE HOSPICE BENEFIT WON'T COVER

By choosing hospice care, you and your loved one have decided to no longer pursue a cure for the terminal illness and related conditions, and/or the doctor has determined that efforts to cure the illness are not working. Medicare won't cover any of the following once someone chooses hospice care:

- **Treatment intended to cure the terminal illness and/or related conditions.** The patient always has the right to stop hospice care at any time, but it is recommended you talk with the patient's doctor about seeking treatment to cure the illness.
- **Prescription drugs** used for the management of the terminal illness and/or related conditions that the hospice care team has determined are not reasonable or necessary.
- **Care from any provider that wasn't set up by the hospice medical team.** Hospice care must be provided by the hospice provider chosen. All care for the terminal illness and related conditions must be given by or arranged by the hospice team. The same type of hospice care cannot be given by a

different provider, unless a decision is made to change to another hospice provider. However, the patient can still see his or her regular doctor if that physician has chosen to be involved in the hospice care.

- **Room and board.** Medicare doesn't cover room and board. However, if the hospice team determines the family is in need of short-term inpatient or respite care services and the hospice arranges for that care, Medicare will cover the stay in a facility. A small copayment may be required for the respite stay.
- **Care received as a hospital outpatient (like in an emergency room), care as a hospital inpatient or ambulance transportation,** unless it's arranged by the hospice team or is unrelated to the terminal illness and related condition.

TIDEWELL SERVICES AT A GLANCE

	Tidewell Hospice	Empath Personal Care	Empath Home Health
Who pays for care?			
Medicare Part A	Yes	No*	Yes
Medicaid	Yes	No*	No
Private Insurance	Coverage varies	Coverage varies*	Coverage varies
Veteran's Benefits	Yes	No*	Yes
Who provides care?			
Physician	As needed	No	No
Registered Nurse	Yes	Admission, as needed	Yes
Social Worker	Yes	No	Yes
Certified Nursing Assistant (CNA)	Yes	Yes	Yes
Chaplain	As requested	No	No
Volunteer	As requested	No	No
Crisis Care	As required	No	No
Coordinator	No	No	No
Aide	No	Yes	Yes
Is transportation covered?	In some cases	No	No
Is medical equipment provided?	All medical equipment related to hospice diagnosis provided	No	No
Are medications provided?	All medications related to hospice diagnosis provided	No	No
Is room and board covered?	Yes, for in-patient and respite care; sliding fee scale for routine care	No	No

*Empath Personal Care offers special rates to Tidewell Hospice patients and families.

THE TIDEWELL TEAM MEMBERS AND PROGRAMS

Tidewell services are provided by an interdisciplinary team. The patient, the doctor and caregivers are a part of this team, too. The team decides with the patient and family the plan of care, which is reviewed regularly and is designed to give you confidence in the management of your loved one's care.

Care is coordinated by an assigned nurse and a social worker who are key members of the Tidewell team. Every effort is made to keep team members consistent. However, there are times when this is not possible. All Tidewell team members have access to the patient's medical information, know the specific plan of care and will be able to answer any questions accordingly. If you are not confident about something that has been explained to you, please do not hesitate to call the Clinical Director listed in the front of this guide.

The regular care team is not available on holidays, weekends and after hours, but Tidewell has an after-hours team available to meet any needs.

Team member roles are defined as:

Primary physician: The patient's primary physician often works closely with the Tidewell team. The doctor reviews the plan of care and may be responsible for the medical management.

Tidewell physician and APRN: The Tidewell physician works with the hospice staff and primary physician. The Tidewell physician is a resource for information regarding hospice medical care and reviews each case at regular intervals. Tidewell physicians are available for visits at the patient's place of residence.

The Tidewell advanced practice registered nurse (APRN) works with the Tidewell physician and is a resource for information regarding hospice medical care and reviews each case at regular intervals.

Tidewell nurse: The nurse provides instruction on how to care for the patient. This includes information about medications, moving a patient, skin care, symptom management and training for the caregiver. The nurse also keeps the doctor updated on the patient's condition.

Tidewell social worker: An illness involves much more than medical problems. Dealing with an illness includes understanding what is happening with the patient and the family unit. The social worker is available for counseling and someone with whom you can share your feelings. They are also there to help you with exploring care options, legal and financial issues and identifying community resources for further assistance.

Tidewell certified nursing assistant (CNA): The CNA is available to provide personal care including bathing, dressing, hair care and other types of personal care to the patient. The frequency of visits is based on the needs of the patient and family.

Tidewell chaplain: Spiritual care is non-judgmental and non-denominational support for patients and families dealing with the meaning and value of life and relationships. For those who confront spiritual and religious issues, the chaplains provide support and guidance. Spiritual care staff works in conjunction with the patient's clergy and within the faith system.

Tidewell grief specialist: The grief specialist provides support and counseling that typically extends to family members for a period of up to one year after the patient's death, but can continue beyond that time when there is a need. Individual and group support is offered.

Tidewell volunteer: The nurse or social worker can explore with you how your loved one can benefit by having a specially trained Tidewell volunteer. The volunteer can provide support to the patient and family by running errands or just being available to talk. All volunteers are prepared for their role with an extensive, ongoing training program. This allows them to comfortably and successfully serve patients and families.

Tidewell pharmacist: The pharmacist works with Tidewell's nurses, physicians and other team members to design an individualized medication regimen for every patient. The goal is to provide medications that relieve pain and symptoms, with minimal side effects and maximum relief.

Tidewell dietitian: The dietitian is available to discuss nutritional needs and other related dietary issues with members of the care team. There are times when the dietitian meets with the patient and family to participate in discussions and provide information related to the intake of food and fluids. If you would like to talk with the dietitian, please ask your Tidewell team.

TIDEWELL SERVICES AVAILABLE 24/7

Tidewell's regular business hours are 8 am to 5 pm, Monday through Friday. However, we recognize that questions or problems may arise after regular business hours or on a weekend or holiday. The service number to use for Tidewell Hospice during this time is noted on the Quick Reference Sheet in the front of this book.

Calls are answered by a Tidewell representative, but occasionally a call to this number goes to voice mail. If that happens, please leave your name, the patient's name and the reason for your call. A nurse will be notified of the message and promptly return your call. Please do not use your telephone while awaiting a return call. All calls are returned promptly so if your call is not returned within 15 to 20 minutes, please call again.

If there is a change in the patient's condition, call Tidewell first. Someone is always available to help 24 hours a day, 7 days a week, 365 days a year.

THE HOSPICE BENEFIT LEVELS OF CARE

These levels of care guide the reimbursement and care for a hospice patient per federal and state regulations. Each care level has different regulations that must be followed to receive that reimbursement. The benefit applies to Medicare and Medicaid recipients.

Routine Home Care

Routine home care is provided if the patient is living in a home environment (ALF, LTC, individual home) and is progressing with an advanced illness. The Medicare Hospice Benefit does not pay for room and board in any facility.

In the nursing home setting, room and board may be paid for through a particular Medicaid program if a patient financially qualifies. Tidewell's social worker is able to explain the qualification requirements.

Short-term Routine Care in Hospice House Care Centers

Short-term stays in the hospice house care centers are available if the needs of the patient are unable to be met in the current setting. The hospice house care centers team begins working with the patient/family at admission to the hospice house to determine and arrange appropriate discharge planning.

Room and board is not covered by Medicare, Medicaid or private insurance. The patient/family is responsible for the cost of room and board. A financial assessment is done by Tidewell's social worker to determine the patient's ability to pay for the cost of room and board and a sliding fee scale is available

to calculate the appropriate amount due. Thanks to the generosity of donors who support the Tidewell Foundation, no one is denied care due to inability to pay.

Respite Care

Caregiving can be challenging and stressful. There are times when caregivers need a break. Respite (or rest) care gives the caregiver the opportunity for time off to recharge. Respite care is part of the benefit provided by Medicare, Medicaid and most private insurances.

How is respite obtained?

The patient is placed in a hospice house or a skilled nursing facility where Tidewell Hospice has a contract. Respite care can last up to five days and can occur as approved by the Tidewell team. The physician may stop by, but this is not necessary since team members provide the facility with all necessary care instructions. The setting is different for respite care, but the care does not change. All situations are unique and respite is considered on a case-by-case basis. If you have questions about the availability of respite care, please consult any of your Tidewell representatives.

How should the patient/caregiver prepare for respite?

All of the patient's medications (except narcotics) and supplies such as ostomy supplies and dressing supplies should accompany the patient in labeled medicine and packaging if going to the hospice house.

Pack the patient's personal items (brush, comb, toothbrush, and so on), as well as any clothing the patient wants. The nurse will advise you if the patient's medications and supplies are to be taken to the receiving facility. This guide should also accompany the patient.

How should the patient get to the facility?

If possible, the family should take and subsequently pick up the patient at respite care. If this isn't possible, transportation needs can be discussed with the Tidewell team.

Continuous Care

Continuous care is the short-term management of a physical, emotional or social symptom. It is designed to prevent a crisis that may lead to hospitalization and includes at least eight hours of skilled nursing care provided by Tidewell in a 24-hour period. This care is provided in the patient's home environment, wherever that may be. If it looks as though this type of care might be needed, the Tidewell nurse will discuss the options with you.

General Inpatient Care (GIP)

Short-term care provided in an approved facility involves direct medical oversight and regular Tidewell staff involvement to address issues of acute pain or other symptoms that cannot be managed well in a home setting. An appropriate plan of care including discharge planning is developed at admission. Admission to GIP must meet prior approval from the Medical Director.

How does the Medicare Hospice Benefit cover hospitalization and GIP?

If the patient has symptoms that are proving difficult to manage at home, a few days in a hospital or hospice house may be necessary. The need for this must be assessed by a Tidewell nurse. The types of problems that may warrant a visit to the hospital or hospice house are increased pain, acute nausea, vomiting or shortness of breath. If such a visit is needed, Tidewell team members help you arrange transportation. The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the terminal illness, including the emergency room. Remember, **CONTACT TIDEWELL DAY OR NIGHT IF YOU ARE CONSIDERING ANY TYPE OF HOSPITALIZATION.**

How is the doctor paid?

For Medicare patients, the current coverage under Medicare Part B continues to cover the doctor's costs for overseeing the plan of care and any direct medical care provided.

The doctors of patients with other insurances are paid according to the specific plan. The doctor usually knows the details or the Tidewell nurse or social worker can find out the information.

TIDEWELL SERVICES IN FACILITIES

People living in long-term care facilities (nursing homes), assisted-living facilities or group homes may receive hospice care. A team of specialized hospice workers, who are familiar with the staff and requirements of these facilities, provides the same support and care for residents as they do for someone living in a private home. Tidewell Hospice works collaboratively to coordinate hospice care with the many facilities in its service area.

The hospice care provided by Tidewell enhances the care provided by the facility staff. Supplies, equipment and medications needed as a result of the advanced illness are provided for patients eligible for a hospice benefit through their insurance. The charge for room and board is not covered under the Medicare or Medicaid hospice benefit, but Medicaid does have a program to help with room and board at the LTC facilities for patients who qualify financially.

Hospice Services Include:

- Ongoing assessment, care planning, monitoring, coordination and provision of care by the hospice interdisciplinary group (IDG), in partnership with the facility staff.
- Hospice CNA services for additional care needs experienced at the end of life. These services will not duplicate the services provided by the facility, but instead will add to these services.
- Financial management and responsibility for all medical supplies and medications related to the terminal illness.
- Determination of the appropriate level of care as determined by the patient's response to symptom management.
- Arranging for any necessary transfers from the facility after consultation with the patient, legal health care decision-maker and facility staff.
- Care and coordination between hospice and the facility staff to meet all of the patient's needs.

Facility Responsibility

- The facility is responsible for contacting the hospice team when there is any change in the patient's condition. This includes falls, skin changes, medication side effects or any complications related to other therapies. At admission, the hospice provides the facility contact telephone numbers to reach the hospice team.
- The facility staff and hospice IDG work closely with the patient and family to develop an individualized plan of care that meets the goals of the patient and family.
- The hospice team meets regularly with the facility staff and the patient and family at a scheduled time as defined by the patient, family or facility, or upon request from any person(s) involved in the care of the patient.

EMOTIONAL CARE

When someone you love has an advanced illness, it can be frightening and overwhelming. You may feel there is nothing more to do, but there are still many choices to be made, even important and joyful things to do.

In facing the advanced illness of a loved one, you travel a wide range of thoughts and feelings. Grief and loss normally begin before someone dies. It is important to realize that there is no right or wrong way to feel or think. Each person finds his or her own way along this path.

It is important to establish a partnership with the Tidewell team members so they can give you the care you need and educate you on what to expect. Understanding the patient's wishes is important to your loved one's peace of mind, as well as your own.

Pain is different from suffering and your team of Tidewell professionals knows the difference. While medicine for the body can help with pain, the human spirit longs for deep connections and opportunities to feel valued and cherished. Take advantage of your social workers or chaplains to help explore love, meaning and hope. Suffering shared is suffering relieved, and Tidewell is here to listen and provide opportunities to heal.

Even in this vulnerable time, when you feel as if you can't go on, you have everything you need to cope right inside you. Share your feelings and let the Tidewell staff remind you that you are strong and capable. Rest often, eat well and slowly breathe through the tough times. You are giving a beautiful gift ... your love. Take good care of yourself during this time so that you can be your best self. Tidewell is here for you and your family because we care about you.

SPIRITUAL CARE

Spirituality, like the body, mind and emotions, is part of our total being; it is central to what makes us human.

Tidewell patients and family members are often at a time in their lives when they are thinking of spiritual issues and gaining insights. Advanced disease may challenge patients and their loved ones with intense spiritual issues that when discussed, benefit the patient and family.

Tidewell honors the spiritual and religious beliefs of its patients and respects patient and family choices. Our professional chaplains and trained spiritual care volunteers are available upon request to support the patient and family.

The Tidewell chaplain is prepared to:

1. Assist the patient and family with the exploration of the relationship with oneself, others, God, a higher power and/or nature.
2. Help the patient and family explore hope, meaning and love with those facing an advanced illness.
3. Assist the patient and family in exploring the meaning and sense of connection with life and death.
4. Help the patient and family work through anxiety, fear, pain, frustration and confusion that may occur.
5. Act as a companion to the patient and family through their spiritual journey.
6. Coordinate with local clergy/spiritual leaders, as requested.
7. Collaborate with the patient and family in the preparation of funeral or memorial services.

Resources available:

- Readings, Prayers and Spiritual Resources booklet
- Other selections are available based on patient/family beliefs and practices

VOLUNTEER SERVICES

Tidewell is proud of its more than 750 volunteers who are active each year. These volunteers, through their compassion and dedication, make it possible for Tidewell to succeed in its mission to provide the highest quality of care for patients and families who are living with advanced illness.

All volunteers are prepared for their role with an extensive training course. This allows them to comfortably and successfully serve patients and families. Tidewell conducts fingerprinting and reference checks, as well as a driver's license screen, on each volunteer in order to ensure the safety of patients, families and staff.

Volunteers support Tidewell patients and families through:

- Companionship
- Running errands
- Administrative tasks in our offices
- Sitting vigil during the dying process
- End-of-life doulas
- Family support calls
- Respite care
- Complementary services
- Tidewell Honors veteran pinnings
- Hospice houses
- Tidewell Treasures
- Craft projects

Tidewell recommends that prospective volunteers wait approximately one year following the death of a loved one to begin their work, but we recognize that each situation and circumstance is different.

For more information on becoming a Tidewell volunteer, please visit TidewellHospice.org or call (941) 441-2061 and ask for a volunteer coordinator in your area.

COMPLEMENTARY SERVICES

Tidewell's Complementary Services department offers a full array of special programs that bring quality of life to those at the end of life. Tidewell Hospice is unique in the variety and depth of complementary services we offer patients. Also, all of these services are free to patients, thanks to the generosity of donors who make gifts to the Tidewell Foundation.

The variety of complementary therapies offered is designed to facilitate:

- Stress reduction for patients and caregivers.
- Pain relief and distraction.
- Opportunities for joy and healing.

The categories of complementary services that Tidewell Hospice employs are:

- Aromatherapy
- Caring touch
- Clowns-humor
- Expressive arts
- Horticultural activities
- Massage
- Music therapy
- Pet therapy
- Reiki
- Reminiscence and life review

Expressive Arts

At Tidewell, we utilize a type of art that is not concerned about the end result, but rather with the creative process. Expressive art diverts the patient's attention from the symptoms that might be causing stress and redirects it. While working on an art project, the patient is not focusing on stress or pain. Several patients have stated: "When I am working with art on a legacy project, I forget about my pain." Some have reached the point that they can say: "When I feel pain coming on, I get out my art project and work on that until the pain goes away."

Expressive Arts volunteers meet with patients wherever they reside. Projects and frequency of visits are individualized. Many patients and families experience joy and relief with these fun, interactive visits.

Music Therapy

There is a relationship between the rhythm of music and the rhythm of the human body. Music has the ability to bring the body into harmony when it is stressed.

Music can assist in controlling pain by encouraging a body to release endorphins. Pulse rate and blood pressure can be modified as emotions are affected by specific music. The rhythm of music can affect the rhythm of the body, such as heartbeat and breathing rate.

There are many kinds of music therapy interventions. They can bring the fun of sing-alongs, aids for breathing and relaxation, spiritual comfort, life review and emotional expression. In addition to our board certified music therapists, volunteers and certified nursing assistants are also trained in the use of music for relaxation and reminiscence.

Pet Therapy

Pet therapy adds to the quality of life: The big brown eyes of a black Labrador looking up at you, welcoming your friendly pets and hugs ... the soft, warm little body that snuggles up with you ... the power of unconditional love. That is pet therapy.

Our pets and our volunteers are very special to Tidewell as they represent a caring connection to our patients and the community in ways that often cannot be verbally expressed. All of our therapy animals are evaluated thoroughly through registered agencies.

Humor

The Tidewell Hospice Clown Alley Circle has an active membership of dedicated volunteers. They regularly visit area nursing homes, assisted living facilities and anywhere their presence is requested.

Massage Therapy, Caring Touch, Reiki

Therapeutic massage is well known for its contribution to pain and stress management and for evoking an overall relaxation response in the recipient. Pain is influenced by any number of physical, emotional and social circumstances. Stress and fear are known to increase the experience of pain. In addition to therapeutic massage delivered by licensed massage therapists, other body/energy work is offered to patients. These include Caring Touch and Reiki.

For more information, call the program coordinator at (941) 552-5914 or ask your nurse or social worker.

TIDEWELL HONORS VETERANS

According to recent census data, more than 106,000 military veterans reside in Manatee, Sarasota, Charlotte and DeSoto counties. They served our country proudly in times of war and peace, at home and abroad.

Tidewell Hospice has had the honor of providing services for thousands of veterans since 1980, and now enhances that care with Tidewell Honors Veterans — a comprehensive program focused on respectfully celebrating veterans and providing care that recognizes the experiences unique to military families.

By honoring the veteran’s contribution to America’s freedom, Tidewell says “thank you” for a job well done and a life well lived. The program gives veterans and their families the opportunity to choose from among a number of services tailored just for them.

Tidewell Hospice is a proud Partner Level-Five participant, the highest attainable level, in We Honor Veterans, a program of the National Hospice and Palliative Care Organization in collaboration with the Department of Veterans Affairs. The Tidewell Foundation provides financial support from donor contributions to ensure that all Veterans Honors programs are offered for free to our patients and community.

Specially Trained

In addition to renowned expertise in caring for those with advanced illnesses, Tidewell’s staff undergoes specific training that helps them identify and deal with issues that are unique to those who have provided military service.

For some veterans, the psychological effects of combat can remain dormant for years, only to re-emerge when they are facing their own mortality. Others may suffer from post-traumatic stress (PTS) or traumatic brain injury (TBI).

Treatment in these cases requires special sensitivity and Tidewell’s clinical team of physicians, nurses, social workers and chaplains are prepared to identify these needs and recommend specific courses of action.

Recognition Ceremony

Tidewell Honors Veterans offers special recognition, upon request, in the form of a unique pinning ceremony.

The pinning event can be as large or small, formal or informal as the patient and family like. Some veterans and their families may decide to hold a gathering of loved ones and friends to share in the ceremony, while others may prefer a more private experience. It is their choice.

Veterans receive a special certificate of appreciation and a unique Tidewell Honors pin that is presented by a current or former serviceman or woman who has been specially trained as a Tidewell Veteran Volunteer.

The ceremony is a moving way to recognize veterans for their service and sacrifice.

Leaving a Legacy

Patients who are dealing with advanced or chronic illness often find it important to leave behind a legacy that can be shared with future generations, and these legacies are an integral part of the Tidewell Honors program.

Although military experience is just a piece of one's life story, for many it is a very important piece.

Using the Library of Congress' Veterans History Project as a guide, Tidewell staff and volunteers encourage veterans to create a legacy by telling their stories. These projects often help with the task of finding meaning in one's life, creating memories of joyful experience and aid in resolution of long-standing conflicts, both internal and external. With assistance from a trained volunteer, the project can be completed in written form or recorded on audio or video.

GRIEF SUPPORT

One of the special services of Tidewell Hospice is its Grief Education and Support Center. Because both patients and their families are important to us, our relationship with the family continues after the patient's death.

Grief is unique to each person in its timing and duration. We have no way of knowing exactly what your path through the process will be. For some, it takes several months before they are able to benefit from support. For others, support is helpful immediately.

When you are ready, Tidewell's grief specialists are here to assist you along your grief journey. You will receive a phone call shortly after your loved one's death to remind you that we are here for you. If you need assistance before the phone call comes, don't hesitate to call Tidewell Grief Care at (941) 845-3061.

It is expected that when a loved one dies there will be many emotions. The sorrow and pain are not a sickness or a weakness, but rather a natural part of adjusting to the physical loss. Grief comes in waves, not stages, and includes good days and bad. In time, with the support appropriate for you, the pain will ease and most people feel a new wisdom and compassion because of the growth experienced during the grief process.

GRIEF SUPPORT GROUPS

Tidewell grief specialists are available in all of Tidewell's offices and family grief centers. They conduct a variety of groups and one-on-one counseling activities, including emotional support for caregivers of veterans. Grief support groups are offered free of charge and are available to everyone.

There are many options for support:

- Individual/family counseling
- Support groups
- Support letters
- Workshops
- Gift of Life celebrations
- Blue Butterfly for grieving children and teens

All family members, from the youngest to the oldest, have their own unique grief journey. Our grief specialists can offer education, validation and support to everyone in the family. Please discuss your needs with Tidewell staff. The team wants you to have the care you need and will contact a grief specialist regarding your request.

The space below — called Thoughts and Wishes —serves as a place where visitors can express their thoughts and wishes to you and your family. Allow them to express themselves here. Read their comments often. Even after they leave, their hearts remain.

Know that we care. Know that we are here. Know that we wish you peace.

THOUGHTS AND WISHES

EMERGENCY MANAGEMENT INFORMATION FOR PATIENTS AND FAMILIES

Tidewell Hospice has developed guidelines to assist patients and families in emergency preparedness in the event of a hurricane or other disaster.

Your case manager will discuss county emergency requirements and your options. Unless specifically dictated by circumstances, the patient may choose to remain in his or her own home. Patients and families who live in evacuation zones or require the care provided in a special needs shelter must have an evacuation plan. You must pre-register with the county for special needs shelter or transportation assistance. Special needs patients will be instructed by Tidewell staff in advance planning.

The special needs shelter should be used as a place of last refuge. The evacuee will not receive the same level of skilled care received from staff in the home and the conditions in the shelter might be stressful. A caregiver must accompany the patient to the special needs shelter.

If you are evacuating to any destination that may include a community shelter, hotel or relative, take this patient guide with you. Your nurse will provide you with a copy of your Tidewell Facesheet and Active Orders, which includes information regarding medication, medical supplies and equipment as well as important contact numbers. The patient must be accompanied by a caregiver to relocate to a designated community shelter.

In the event of a situation that causes the patient to leave his or her place of residence, please notify a member of the Tidewell team of the address and phone number or the name of the facility.

If county transportation is being provided, please be prepared to leave immediately upon its arrival. IF YOU HAVE ANY QUESTIONS, PLEASE CALL COUNTY EMERGENCY MANAGEMENT.

Charlotte County (941) 833-4000

DeSoto County (863) 993-4831

Manatee County (941) 749-3500

Sarasota County (941) 861-5000

EVACUATION CHECKLIST

Listed below are actions to take BEFORE evacuation. If evacuating to a special needs shelter, the patient and caregiver **MUST** be ready before the county evacuation transportation vehicle arrives. Special needs evacuations must be completed prior to road congestion. Even if the sun is shining, the storm is on its way! Please remember, many registered citizens will need assistance. The local Emergency Management will call with an estimated time of the transportation pick-up. The types of vehicles used are transit buses, school buses or ambulances, which provide transport to shelters or medical facilities as determined by your application.

Here are some things you should do before evacuation.

Do Now:

Make plans for pets to be taken care of by a veterinarian, family or friend.

When Evacuating:

1. Pack a bag and be ready to go with:

- Tidewell Hospice 24-hour telephone number.
- Tidewell Active Orders, and Patient/Family Resource Guide.
- Medications for 10 days.
- Advance directives, including Do Not Resuscitate order, if applicable.
- Walker, wheelchair and other medical equipment.
- If oxygen dependent, bring all equipment if so instructed by the County Emergency Management.
- Clean clothes for three days.
- Extra eye glasses.
- Blankets and pillows.
- Personal hygiene items.
- House keys and car keys.
- Personal phone book or list of important numbers.
- Important papers, including identification, sealed in zip-lock bags.

- Folding chair, lawn chair.
 - Reading material.
 - Non-perishable snack items while shelters become fully operational.
 - Non-perishable food items if you require a special diet.
2. Call family members, including those out of state, to inform them of evacuation plans.
 3. It is important to turn off electricity, water and gas, if possible.
 4. Please have all pets evacuated before evacuation transportation arrives.

Evacuation to a special needs shelter

Patients and caregivers who will be sheltered need to know the following:

- If the patient has a caregiver, the caregiver must accompany the patient to the special needs shelter.
- A special needs shelter can accommodate one caregiver at a time. Other family members and friends should go to a regular shelter.
- Service dogs will be allowed to go to the special needs shelter. Check with your county emergency management office regarding their requirements for sheltering animals.
- The caregiver accompanying a patient will have floor space provided. The caregiver must provide his or her own bedding and cot.
- Caregivers who regularly assist the patient in the home are expected to continue to provide the same care in the shelter.
- Conditions in a shelter might be stressful and the patient may not receive the same level of skilled care that he or she received from staff in the home.
- As a last resort only, dogs and cats will be allowed in the designated pet area of the Special Needs Shelter.

HURRICANE STAGES — WHAT TO DO

Hurricane Season: June 1 through November 30

Evacuation Areas: Barrier island and mobile home residents will be ordered to leave their home for all hurricanes.

Hurricane Watch: An advisory issued by the National Hurricane Center when hurricane conditions are a possible threat to a certain area, usually issued 24 to 48 hours before hurricane eye landfall. This is the time to complete preparations.

Hurricane Warning: An advisory issued when winds of at least 74 mph, high water and storm surges are expected to reach a specific area within a period of 24 hours. Stay tuned to your local official hurricane radio or television station. If you receive word to leave your home — Go!

Eye of the Hurricane: The calm area near the center of the hurricane which takes from several minutes to an hour to pass. Stay inside!

Food and Water

- Use perishable foods first. Frozen foods may be usable for up to three days.
- Set refrigerator on the coldest setting. Open only when absolutely necessary and close quickly. Use ice chest so refrigerator doors can be left shut. Place frozen containers of water in freezer, wrap freezer in blankets.
- Use gas stove, canned heat (Sterno®) or chafing dishes. Never use charcoal grills inside the house — the fumes can kill.
- Stockpile nonperishable foods early: canned meats in meal size cans, fish, soups, stews, juices, fruits and vegetables; jars of cheese spreads, peanut butter and jelly; dried fruits, crackers, cookies and nuts; dried, canned and long-life milk; bottled and canned soft drinks. Don't forget baby food and pet food.
- Have plenty of paper plates, napkins, cups, towels, plastic utensils and garbage bags on hand.
- Canned, liquid, high-calorie, high-protein drinks such as Sustacal® and Ensure® may be used as a dietary supplement.
- If there is any doubt about whether food is still good, throw it out. Discard frozen food unless ice crystals are still visible. Throw out food that has come in contact with flood water.

- Purchase bottled water or stockpile containers of tap water to be used for drinking and cooking. As you empty liter soda bottles, rinse and fill with water and refrigerate for drinking water and cooking.
- When tap water is unsafe, officials will issue boil-water orders. Purify water by boiling it for 10 minutes. The flavor of boiled water can be improved by adding a pinch of salt to each quart.
- Before the storm, clean bathtub with bleach. Seal drain. Fill tub with water for bathing and to be poured into the toilet tank to flush the toilet.
- If you use a generator, extreme caution is required. Never run your generator inside your home or garage or in any other enclosed space. Always read and follow the manufacturer's safety and operating instructions.

Avoid the rush — avoid perishables. Buy before the season starts.

Pets

If you do not need to evacuate your home, prepare for your pets' needs prior to the storm.

- Bring pets inside if you remain at home during a storm. Remember that the noise of a storm can frighten a pet, so if possible, keep them within sight of the family.
- Keep a good supply of newspapers for pet's sanitary needs. The use of bathrooms, the utility room or enclosed garage will be easier to clean.
- Feed your pet moist or canned food to preserve water.

If you need to evacuate your home, shelters may not take your pet. Make advance preparations for the care of your pets.

- Make arrangements for your pet's safety prior to your evacuation. Do not plan to leave your pet alone in your home.
- Leave your pet with a friend or relative, with food and a favorite toy. Prearrange to board your pet in a kennel.
- Call your county Emergency Management to find out which shelters take pets and what arrangements must be made to bring your pet to a shelter.
- Put an identification tag on your pet if it does not have one.

INFECTION CONTROL

Protecting the patient and caregiver from infections can be done using some basic rules. The nurse will be glad to review these with you.

1. Wash hands. Caregivers should wash their hands frequently, both before and after providing care, food prep and eating. Do not forget the patient's hands. Waterless hand sanitizer products are acceptable.
2. Use liquid soap. Be sure to wash between fingers, count to 20 as you scrub, rinse well using as warm water as possible and dry completely. Use a fingernail brush when possible. If the sink area has many users, keep a roll of paper towels nearby instead of a cloth towel.
3. Use gloves. Disposable gloves need to be used when the caregiver may be in contact with blood, bowel movements, urine or other bodily fluids. As soon as the task is done, throw the gloves away and wash hands well.
4. Clean up patient area. Trash that has blood or other body fluids should be placed in a plastic, leak-proof bag for regular trash disposal. The Tidewell nurse will advise you if soiled items need to be put in a special red bag and picked up by Tidewell staff. Clean spills of bodily fluids immediately with a 10 percent bleach and water solution (one part bleach to 9 parts water). Air out the room when possible.
5. Needles, syringes and other sharp objects. If the patient uses these items, dispose of them in a sharps container provided by Tidewell. Keep out of reach of children.

REMEMBER: THE MOST IMPORTANT INFECTION CONTROL MEASURE IS WASHING YOUR HANDS.

SAFETY

Special care should be used to prevent falls and injuries. If help is needed when walking, support your loved one on the weakest side. Put one arm around the waist and the other forearm and hand in front of the shoulder. If a gait belt has been provided and your Tidewell nurse has provided education on its proper use, make sure it is on prior to your loved one's transfer.

When your loved one is getting up out of bed, remind him or her to sit up on the side of the bed for a few minutes. A change in position may cause dizziness or unsteadiness. If your loved one becomes lightheaded, stay with him or her. When transferring, use care to transfer across the shortest possible distance. If in a hospital bed, adjust the level of the bed to reduce strain on your back.

How to help

- Lock wheels of beds and wheelchairs to prevent slipping.
- Remove throw rugs to avoid tripping and falling.
- Remove or relocate electrical cords running across the floor.
- Use bath mats or non-slip stickers in bath tub and shower.
- Place the bed near a bathroom, if possible, or place a commode near the bed.
- Do not use slippery shoes or slippers.
- Keep your back straight when lifting your loved one, and bend and lift from your knees and hips. Stand as close as possible and keep feet spread for a firm base and good balance.
- Keep the electric bed in low position.
- Ask your nurse if fall pads are appropriate.
- Have walkways and stairs well lighted and clear of objects and use nightlights.
- Install grab bars near toilet and shower/bath tub.
- Be aware of side effects from medications.
- Rise slowly from sitting or lying down to prevent dizziness.
- Use a baby monitor, chair or bed alarm to monitor the patient.

- Do not smoke in bed or when oxygen is in use.
- Have smoke detectors near bedrooms and test monthly.
- Keep portable heaters at least three feet from objects.
- Do not use oxygen near any heat source.
- Do not use petroleum-based products, such as Vaseline®, when using oxygen.
- Keep medication out of the reach of children.
- Follow medication instructions, double checking correct medication-route-dose-time.
- Use good lighting when dispensing medications.
- Follow the written instructions provided by the hospice medical equipment vendor for the safe use of equipment and the safe handling and storage of oxygen.
- Keep electrical appliances a safe distance from water.
- Do not overload electrical outlets.

When to call Tidewell Hospice

- If an accident or fall occurs
- If your loved one complains of severe pain
- If any part of the body (arm, leg, hip, etc.) is in an unusual position
- If there is fluid draining from your loved one's mouth, ears, nose or if he or she is bleeding
- If you are transferring your loved one and he or she begins to fall, gently assist him or her to the floor. Do not attempt to stop or break the fall.

INSTRUCTIONS FOR THE SAFE HANDLING OF BIOMEDICAL WASTE IN THE HOME

The State of Florida Department of Health defines biomedical waste (BMW) as any solid or liquid waste that may present a threat of infection to humans. The term includes, but is not limited to, non-liquid human tissue and body parts, discarded sharps (needles and syringes), human blood, human blood products and body fluids. The following are also included:

- Used absorbent materials (i.e., dressings) saturated with blood, blood products, body fluids or excretions or secretions contaminated with visible blood.
- Non-absorbent, disposable devices that have been contaminated with blood, blood products, body fluids or excretions or secretions contaminated with visible blood but have not been treated by an approved method.
- Examples of BMW include:
 - Blood and blood products.
 - Any internal body fluids.
 - Dressings, diapers, pads or bandages saturated with blood or blood products to the point of dripping.
 - Disposable devices (i.e., latex gloves, tubing, catheters) contaminated with blood or blood products.
 - Used needles and syringes or lancets.

Instructions:

1. Thorough hand washing is the most important way to protect against disease causing germs. Ask your nurse to demonstrate proper hand washing technique, if you are unsure.
2. Your nurse will give you specific instructions in collection and disposal of any liquid or solid waste which is considered biohazardous.
3. Your nurse will instruct you in the proper technique used to change soiled dressings and their disposal. Tidewell supplies you with the necessary red bags in which to place items considered biomedical waste.
4. Tidewell staff, usually the nurse, will remove the red bags from your home.

- 5.If injections are part of the patient's care, the nurse will instruct you in the proper technique.
- 6.Tidewell supplies hard plastic boxes that are resistant to punctures, called sharps containers, for used needles and syringes.
- 7.The nurse caps and tapes the sharps box and removes it from your home when it is 2/3 full or no longer needed.

If you have any questions regarding the handling of biomedical waste, please ask your nurse or call the Tidewell office.

CARE FOR THE CAREGIVER/FAMILY/FRIENDS

Caring for the hospice patient at home can be rewarding, although it can also be physically and emotionally challenging. It is important that you take care of yourself. Rest and relief are necessary for you to be physically and emotionally able to care for your loved one.

Try to get at least six hours of sleep each night and take naps when the patient is sleeping during the day. If you become exhausted, let your Tidewell team know. We may be able to suggest an easier way to meet the patient's needs or support you with volunteer assistance. You may not have time to do everything you normally do. Limit time spent on things like household chores or yard work; find someone to do it for you.

Take time for yourself. Many caregivers become so absorbed in meeting the patient's needs that they neglect their own. Get out for a breath of fresh air or a change of scenery. Even a brief walk around your neighborhood can make a big difference. Relax in a warm bath or read a good book. Let yourself be alone for a short while to clear your head. By taking care of yourself, you are also making sure that you will be able to continue to give your loved one the care and attention they need.

Eat three meals a day. It is easy to forget to eat when you are under stress, but you need good nutrition now more than ever to get you through the day.

Accept emotional support. A worry is often easier to handle when it is shared with someone who cares. Talk to friends and family about your feelings and concerns, or share your feelings with the members of the Tidewell care team.

Do not be afraid to cry. Tears can be healing. Feelings held inside drain your energy.

Not everyone copes the same way. Each member of your family is unique, so each will handle this trying time in his or her own way. All of you will experience a wide range of emotions during your caregiving days. Tidewell's staff is available to listen and discuss these feelings, knowing that it is often easier to deal with emotions that are shared. Concerns of the patient also need to be discussed.

There can be relief for patient, family and friends when old hurts are forgiven, love is reaffirmed and respect for the wishes of the dying person is expressed. The experience and support of the Tidewell staff can help make this happen.

ESPECIALLY FOR THE CAREGIVER

For most people, taking care of a person who is seriously ill is a new experience. As with all new experiences, there are also new feelings. You should know that these feelings are not unique to you alone, but are shared by many who care for a terminally ill person. Accept these feelings. They are neither good nor bad — they are your feelings.

You may feel guilty or angry. Expressing negative emotions can be difficult in these times of stress. However, avoiding discussions about painful feelings can put up walls. Try to accept that all feelings are natural and normal.

There may be times of humor and laughter. As strange as this may sound, a good joke is great medicine. Take time to see the humor in the moment — it helps everyone feel good.

Feeling overwhelmed is common. Be specific about your needs when friends and family ask what they can do to help. Often, people want to help but need specific tasks. Accept the offer. Give the directions that are necessary; then, trust the other with the responsibility of your request. Prioritize, because you cannot do it all. Accept that some of your everyday tasks will go undone or will be done less frequently.

Caring for another feels good. Meeting the needs and sharing care tasks that bring comfort to the patient often help us see the best in ourselves and in each other.

Anxious feelings and worries often intrude on thoughts and even sleep time. Share your worries with your Tidewell team members. They can often provide the information or reassurance you need. They have experiences to share with you, and they want to help reduce your anxiety.

You may feel resentment toward others. It is hard when those around you are able to do everyday things while you're busy caring for your loved one. It is even harder when you are the one losing a loved one and they are not. Do not go through this alone. Gather your circle of support and take time for yourself. It is important to plan time away from caregiving. Celebrate special events, holidays and occasions.

Appreciate yourself. What you are doing is very special. Give yourself credit for this caring work you are providing. It is truly a gift of the heart.

COMMUNICATION

One of the most important aspects of being a part of the Tidewell team is to be sure that all members of the team understand each other. That includes information presented to the patient and family members by the Tidewell staff members, as well as what the patient and family have to tell the Tidewell team.

Since the patient and the family are the most significant members of the team, the Tidewell team members need to always make sure that you understand what we are sharing or explaining. There may be times when the nurse or social worker uses medical terms that may be unfamiliar to you. Please ask for clarification if you don't understand. We want you to feel confident during every step of the process of caring for your loved one.

In addition, there may be times that a question comes up after the Tidewell team member leaves the residence. If it is something that you need to know the answer to right away, please call the number that is provided to you. If it is something that can wait, make a list of the questions you have and discuss the issues with the Tidewell staff when they come for the next visit.

One way for Tidewell caregivers to communicate is by using an electronic medical record. They record visit information on a computer before leaving the residence. This ensures that the entire team has access to the most up-to-date information and addresses your needs efficiently.

If at any time you feel that you have issues that are not being addressed, please call the clinical director identified in the front of this guide. It is Tidewell's goal to meet your hospice-related needs the best way possible.

COMMUNICATING IN OTHER LANGUAGES

Positive, culturally competent, compassionate and clearly understandable communication is an essential element to exceptional care and services. Tidewell is committed to helping those we serve understand the information we provide and always communicate with you and your loved ones in these ways.

In some situations, there are language barriers between people who are not comfortable speaking or understanding the same language. In these situations, the Tidewell team will identify the most appropriate way to communicate the care needs of the patient and family. It may involve a family member or friend who acts as the translator between Tidewell and the patient and/or caregiver. Other times, the Tidewell staff member may speak the same language and can communicate with patients and/or caregivers.

The Cuidando con Carino, Compassionate Care Helpline is a toll-free phone line that offers information and resources for people living with or caring for someone with a serious illness. People calling the Helpline reach bilingual information specialists who can answer questions about hospice, helping a loved one with grief and loss, family caregiving and advance healthcare planning. Important bilingual written information can also be provided free of charge. The helpline can be reached at (877) 658-8896.

Another way that Tidewell provides language interpretation services is through the AT&T Language Line. Every Tidewell team member has access to a telephone number that puts an interpreter on the telephone. The interpreter listens to what the staff member needs to explain to the patient and/or caregiver and then communicates that information in their native language. The interpreter also listens to what the patient/caregiver says and tells the Tidewell staffer what was said in English.

Remember, if you have any difficulty understanding what is being said, please ask the Tidewell team member to explain or to find an interpreter.

RELAXATION TECHNIQUES

Relaxation can assist you emotionally and physically. It can help control pain, as well as decrease anxiety, depression and other distressing emotional symptoms.

You will need:

1. A quiet environment. Make sure you are physically distanced from activity in the home. For example, turn off the television.

2. To be in a relaxed posture. If sitting, place your feet flat on the floor with your hands in a comfortable position. If reclining, keep your legs and arms stretched out comfortably. Crossing your limbs may create tension.
3. To close your eyes to focus attention and to avoid distraction.
4. To remain mindful of the value of this time with your loved one or yourself. If you are not centered and focused, these techniques will not help. Prepare yourself before beginning the relaxation exercise. Be mindful of the present moment. Being centered and focused will make these techniques more helpful.

Initially, you may want to do relaxation exercises for only 10 minutes, increasing to 20 or 30 minutes over time. This may vary depending on your comfort level. Some people are more comfortable with quiet than others.

Overall, we live in a culture that is not used to lengthy periods of silence. Try not to begin relaxation exercises if you have recently eaten a meal, or are hungry and anticipating a meal.

Suggested script

To begin, try to position your body comfortably. Be sure your body is well supported. Close your eyes to block distractions and turn your attention to your breathing. Note your own rhythm.

With each breath out ... imagine any negative thoughts or fears leaving your body ... clear your lungs and body for positive images.

With each breath in ... imagine your body filling with peace ... love ... from the top of your head ... down your neck ... and arms ... to your fingertips ... traveling through your chest ... to your legs ... to the tips of your toes.

Give special attention to any part of your body that seems to need nurturing ... imagine the positive breath filling that space ... comfort it ... spend a few moments here ... enjoy the peace ... embrace the stillness.

When you are ready ... gradually begin to notice your surroundings ... the sounds ... the smells ... the textures ... continue awareness of your breathing ... when you are ready ... gently open your eyes. Take in the sights of your surroundings ... and continue your day feeling the peace and love inside you.

Feel free to make changes to this script or create your own to meet your needs. Contact a member of your Tidewell team for more information.

CARING FOR THE PATIENT

Providing care for your loved one can be rewarding, but you also may have many questions about how you can help, what not to do and when to call Tidewell Hospice.

AGITATION AND RESTLESSNESS

Agitation is a commonly occurring symptom in patients near the end of life, yet it often surprises the caregiver and family when it occurs. A loved one who is usually calm may unexpectedly and suddenly experience significant mood and behavior changes. As with other symptoms, it is important to recognize and treat agitation early.

Signs and symptoms of agitation

- Restlessness and inability to be still
- Yelling and/or striking out
- Trying to get out of bed
- Thrashing
- Picking at clothing or bedding
- Frequently requesting to urinate
- Anger
- Confusion and/or paranoia
- Hallucinating
- Insomnia
- Difficulty concentrating or focusing attention
- Trying to go somewhere, such as the store or to work.

Let Me Teach You guides are available from your Tidewell team or online at ***TidewellHospice.org/Let-Me-Teach-You/***

How to help

- Stay calm. If you appear anxious, it could affect your loved one's behavior.
- Call the Tidewell Hospice RN. The RN will evaluate the patient for possible causes of agitation and work with you and hospice team members to treat the agitation.
- Administer prescribed anxiety medications according to medication directions if they are available.
- Stay with your loved one to help keep them safe.
- Talk soothingly to your loved one.
- Create a calm and soothing environment. This can include reducing excess noise, dimming lights, or softly playing music.
- Use lotion to gently stroke your loved one's hand or foot.
- Do not correct or contradict what your loved one says; it may increase their agitation.

The following information will be helpful to Tidewell Hospice:

- When did the agitation begin?
- What, if anything, seemed to trigger the agitation?

Please discuss this with the nurse when he or she visits, or call Tidewell to talk with a member of the team.

ANXIETY

Anxiety is a feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome.

Signs and symptoms of anxiety

- Feeling jittery
- A fast heart rate or breathing rate
- Sweating
- Excessive worrying
- Difficulty sleeping
- Difficulty concentrating

- Difficulty getting comfortable
- Having trouble relaxing

There can be many reasons a person feels anxious. Some common causes of anxiety include feelings of fear (fear of the unknown, fear of pain, fear of abandonment), loss of control, or loss of independence. Additionally some medications and food products (for example, caffeine found in coffee and tea) can cause feelings of anxiety.

How to help

- Talk to him or her.
- Suggest breathing slowly and deeply for a few minutes
- Play calming music
- Suggest he or she write down thoughts and feelings
- Look at relaxing images (for example, relaxing photographs)
- Ask visitors to come at another time
- Create a calm, quiet environment
- Gently rub the hands or feet
- Reduce caffeine intake

Breathing Assistance: If the person uses oxygen, is he or she wearing it? Have you or someone else checked it to make sure it is functioning properly?

Medications: Has the person taken the prescribed medications?

- Anxiety medication
- Pain medication
- Medication for shortness of breath
- Other medication

Please discuss this with the nurse when he or she visits, or call Tidewell to talk with a member of the team.

BATHING

Bathing promotes cleanliness, circulation and comfort, and also helps refresh the patient in body and spirit.

Before you start a bath

- If your loved one has an electric bed, raise the level of the bed to reduce strain on your back.
- Consider offering a prescribed pain medication at least 20 minutes before the bath to reduce any discomfort.

What you need

- Gloves
- Mild soap
- Soft wash cloth and towel
- Wash basin
- Lotion

What to do

- Gather the bathing supplies before starting.
- Keep the body covered and expose only the part of the body that is currently being bathed.
- Begin with the face, washing with warm water and patting dry.
- Work from head to feet, including the back. Soap an area of skin, rinse well and pat dry.
- Once you have completed washing the feet, discard the bath water.
- Obtain fresh water and wash the genitals and buttocks, washing from front to back and drying thoroughly.
- Dry all skin folds thoroughly to prevent chapping.
- Apply lotion to any red areas and rub gently. Apply lotion to the back and consider giving a soothing back rub.

- If unable to tolerate a head-to-toe bath due to pain or fatigue, attempt a partial bath, washing the face, hands, back and genitals.
- Remember to place side rails, if present, in the upright position after the bath.

Tidewell certified nursing assistants (CNAs) are available to assist with personal care when it is needed. Please discuss this with the nurse when he or she visits, or call Tidewell to talk with a member of the team.

BLEEDING PREVENTION

Patients may be more likely to bleed because of the effects of their illness. Talk with the Tidewell nurse if there is any unusual bleeding. The following are guidelines to assist in the prevention of patient bleeding:

1. Avoid using sharp objects.
2. Use an electric shaver.
3. Use a soft toothbrush, sponge toothpaste, or a washcloth to clean teeth. Floss carefully.
4. Rectal medicine should be given carefully and with a generous amount of water-soluble lubrication.
5. Avoid injections.
6. Help patient blow nose gently.
7. Move furniture out of the patient's way and turn on lights.
8. Make sure patient wears a seatbelt in the car.
9. Always put slippers or shoes on the patient's feet when out of bed.
10. If bleeding is likely to occur, it is helpful to have dark towels on hand to absorb blood.

Report any of the following observations to your nurse:

1. Blood in the urine, stool, sputum or vomit.
2. Black stools (tar-like).
3. Vomit that is dark brown or bright red.
4. Bloody nose (one that is difficult to control).
5. Multiple bruises.
6. Many small, reddish-purple dots under the skin.

If bleeding occurs, apply pressure if possible, and call Tidewell.

BREATHING AND TROUBLE BREATHING

A number of health problems may make it hard for the patient to get oxygen into the lungs. This can cause the patient to have trouble breathing.

The medical term for difficult or troubled breathing is dyspnea is a medical term. You may also hear it referred to as shortness of breath, hard to breathe, heavy chest or not getting enough air.

This feeling of having difficulty breathing can be very scary and make your loved one feel anxious. There are things that you (and others) can do to help the person when this shortness of breath feeling occurs.

How to help

- Proper positioning. Have the patient sit upright and lean forward slightly or stand and lean forward slightly.
- Keep the room cool with circulating air (use a fan).
- Make sure the area is calm and peaceful, allowing the patient to relax.
- Stop any activity and let the person rest.

Breathing Assistance: If the person uses oxygen, is he or she wearing it? Have you or someone else checked it to make sure it is functioning properly? Suggest trying pursed lip breathing (smell the roses, blow out the candle).

Medications: Has the person taken the prescribed medications?

- Anxiety medication
- Pain medication
- Medication for shortness of breath
- Other medication

Please discuss this with the nurse when he or she visits, or call Tidewell to talk with a member of the team.

CONSTIPATION AND DIARRHEA

Constipation

Constipation is a condition of the digestive system that occurs when stool becomes hard inside the bowel and/or is difficult to expel.

Some of the causes of constipation

- Not drinking enough water.
- Not enough fiber in the diet.
- Certain medications.
- Lack of activity.
- Slowing down of the digestive system due to aging.
- Certain illnesses such as Parkinson's disease and diabetes.

It is important to have regular bowel movements even if the person is eating only small amounts of food. The Tidewell nurse and physician can work with you to come up with a proactive plan to prevent constipation or if the person has constipation, to treat it effectively. Tell the nurse about all “over-the-counter” being used as well as prescription medications.

Interventions that can prevent or treat constipation

- Prune juice
- Stool softeners
- Laxative tablets
- Laxative liquids
- Fiber powders added to drinks
- Suppositories
- Enemas

Early detection of constipation allows for less invasive interventions and avoids possible future discomfort.

Talk to the Tidewell nurse if:

- Patient has not moved bowels in 3 days.
- Patient does not move bowels within one day of taking laxative.
- Patient has severe, constant cramping or vomiting.

Diarrhea

Diarrhea, accompanied by stomach cramping, can be a problem. If diarrhea is present keep a record of how often it occurs and notify the Tidewell nurse.

How to help

- Offer a bedpan or commode at least every two hours, or more often if needed.
- Increase fluid intake and encourage sipping slowly.
- Offer clear fruit juices (not fruit) as well as water. Avoid drinks with caffeine (including cola, coffee and tea).
- Give frequent small meals such as oatmeal, strawberries, potatoes, apricots, pears, bananas, white rice, applesauce or toast/crackers, gelatin and/or creamy/smooth peanut butter.
- Check with the nurse that laxatives and stool softeners have been discontinued.
- After each loose stool, wash the rectal area with mild soap and water and apply skin protective lotion.
- Make sure the commode or bedpan is readily available nearby.
- If in bed, place in a sitting position for a bowel movement by raising the head of the bed.
- Do not remain on the bedpan/commode for long periods of time.
- Always wash your hands after using the toilet, commode or bedpan.

When to call Tidewell Hospice

- If there is blood in the stool.
- If there is nausea or vomiting.
- If there is increased abdominal pain.

Healthy Bowel Recipe

½ cup applesauce

½ cup prune juice

½ cup whole bran

¼ cup honey (omit if diabetic)

Mix and store covered in refrigerator

Take 1 to 2 tablespoons, 1 to 2 times daily

Drink 1 cup hot liquid after taking mixture.

FATIGUE

What is fatigue?

Fatigue is the feeling of being tired physically, mentally and emotionally. It means having less energy to do the things one normally does or wants to do. Fatigue in hospice patients is different from the fatigue of everyday life, which is usually temporary and relieved by rest. Rest may not always relieve the fatigue of a hospice patient. This kind of fatigue can be as distressing as pain, nausea, vomiting or depression.

Fatigue can:

- Vary in its unpleasantness, severity and the amount of time that it is present.
- Be overwhelming and hinder the person's ability to feel well.
- Make being with friends and family difficult.
- Decrease one's ability to continue normal daily activities.
- Make it difficult to follow a treatment plan.

There are many things that can contribute to or cause the feelings of fatigue, including low blood counts, medical treatments or interventions, pain and emotional distress, medicines, poor nutrition and inactivity.

Education

By understanding fatigue one can cope better and reduce distress. Often a family member who participates in the education can help the patient talk about fatigue.

Self-care measures to reduce fatigue

- Prioritize activities according to how important they are to the person and when he or she has the most energy.
- Offer help and allow others to do some of the patient's tasks.
- Place often used items within easy reach to save energy.
- Establish a structured daily routine.
- Use methods to reduce stress, such as deep breathing, visual imagery, meditation, prayer, talking with others, reading, listening to music, painting or any other activity that gives the patient pleasure.
- Keep a journal.
- Balance rest and activities. Schedule activities so there is plenty of time for rest that does not interfere with nighttime sleep. Shorter rest periods are reported to be better than one long one.
- Talk to the Tidewell nurse about how to manage pain, nausea and depression.
- Unless instructed otherwise, provide a balanced diet that includes protein and adequate fluids as tolerated.

FLUID RETENTION

Patients often retain fluid in areas such as the legs, ankles, feet and hands. This is called edema. A doctor or nurse who is familiar with the patient may be able to give you more information about fluid retention, but here are four common causes of edema:

- Heart failure. The weakened heart is unable to pump blood properly to the extremities.
- Poor nutrition and low protein levels. Proteins help to hold salt and water inside the blood vessels so fluid does not leak out into the tissues. If protein levels are too low, fluid is retained.
- Inactivity. If a person stands or sits still for long periods of time, there is a much higher chance of swelling.
- Certain types of cancer can cause edema.

How to help

1. Elevate the affected area above the heart if possible. If not possible, elevate as able.
2. Avoid tight clothing, belts, socks, rings or shoes.

3. It may be helpful to avoid salt. Check foods for high salt content.
4. The doctor may order a water pill or diuretic, which helps eliminate excess water through the kidneys.
5. Keep the person moving.
6. If the patient is unable to get out of bed ask the nurse to show you how to do range-of-motion exercises.

ITCHING

Itching can result in restlessness, anxiety, skin sores and infection. Common causes of itching include dry skin, toxins in the blood, allergies, side-effects of medications, chemotherapy, radiation therapy and tumor growth.

How to help

- Apply skin creams with a water-soluble base two to three times a day, especially after a bath when the skin is damp.
- Use warm instead of hot water for bathing.
- Add baking soda or bath oil to patient's bath water.
- Wash skin gently using a mild soap.
- Use baking soda instead of deodorant.
- Keep patient's nails clean and cut short.
- Encourage the person to wear loose clothing made of a soft fabric.
- Change bed sheets often.
- Keep room cool (70 to 78 degrees) and well ventilated.
- Encourage the person to drink as much water and other fluids as possible.
- Provide diversions like television, radio or books.
- Administer medications for itching as ordered by doctor.

What not to do

- Do not use hot water for baths.
- Do not scrub patient's skin.
- Do not cover patient with a lot of bedding.
- Avoid scented and alcohol-based products on skin.
- Avoid using harsh detergents.
- Avoid alcohol and coffee.

When to call Tidewell Hospice

- If a rash develops.
- If skin is red and hot to the touch.
- If skin sores develop.
- Itching is causing distress.

MEDICAL EQUIPMENT

The use of medical equipment can help patients remain in their place of residence. By having medical equipment available, care needs may be handled in a safe, efficient and effective manner.

The Tidewell nurse will evaluate the need for medical equipment and arrange to have it delivered. A representative of the medical equipment company will call to coordinate a delivery time.

Instructions for the medical equipment will be provided by the person making the delivery. Feel free to ask questions that will help you feel comfortable operating the equipment. The Tidewell nurse is also available to provide assistance.

When the equipment is no longer needed, the Tidewell nurse will arrange for the medical equipment company to pick it up. If you must have the equipment removed earlier than the next business day, please tell the nurse or call Tidewell to coordinate with the medical equipment company.

MEDICATIONS

Medications come in different forms, including pills, liquids, inhalants, patches, suppositories and ointments.

If the patient is having a difficult time swallowing medication, please notify the Tidewell nurse. Many medicines are available in different forms, depending on the patient's needs.

How to help

- Read the label before giving the medicine.
- Make sure the medicine is taken exactly as it is written on the prescription or as ordered by the prescriber.
- Give routine medicine on a regular schedule.
- Use "breakthrough" or "in-between" medicine as ordered and instructed by the Tidewell nurse and prescriber.
- Call the Tidewell nurse if the medicine does not seem to be working.
- Notify the Tidewell nurse of any side effects to medication.
- Keep a written schedule and record of when and how often medicines are taken.
- Avoid mixing alcoholic beverages with medicine. Consult the Tidewell nurse if you have questions.
- Call the Tidewell nurse with questions regarding the dosage and/or medication changes.
- Make sure there is enough medication on hand. Contact the Tidewell nurse if you think you are running low (less than a two-day supply).

KEEP ALL MEDICINE OUT OF REACH OF CHILDREN, PETS AND CONFUSED ADULTS.

What not to do

- Share medications with anyone else.
- Crush pills without first checking with the Tidewell nurse.
- Take or give more than the amount of medicine than is ordered.

How to help

- To ease swallowing pills, moisten the mouth with water or add pills to applesauce or pudding. Some pills may be cut in half. Please check with the Tidewell nurse before crushing any pills since some pills can NOT be crushed or split.
- If giving a medication rectally, it is best to administer after a bowel movement, if applicable. Using a glove, lubricate one finger and insert the medication at least 2/3 of the finger's length.
- When using liquid medicine, slightly tilt the patient's head upright and slowly pour the medicine down the side of the mouth.
- When administering tablets under the tongue or between the cheek and gum, moisten the area with two to five drops of water and then place the pills in the area as directed by the Tidewell nurse.
- Use the pocket in the back of this guide to store the patient education leaflets that come with medications.

Comfort Kit

If a comfort kit is placed in the home, keep it closed and in the refrigerator (away from the family's food). The Tidewell nurse will provide directions and instructions on its use when the time is appropriate. Do not open the kit until a Tidewell nurse instructs you to.

MOUTH CARE

Cleaning the mouth provides several benefits for the patient. It helps to prevent sores or infection and may help improve the patient's appetite. Cleaning the mouth can also help with the uncomfortable condition of dry mouth, which can be caused by mouth breathing, oxygen therapy, poor mouth care, a side effect of medications or a complication of radiation therapy. If the person is able to perform mouth care, allow him or her to do so.

How to help

- Raise the head of the bed and place a clean cloth under the patient's chin.
- Remove any dentures and place them in a container of water.
- Have patient sip water to moisten mouth.
- Apply toothpaste to the brush and gently brush teeth, gums and tongue.
- Allow the patient to sip water and spit alternately.

- Finish with cool water and/or mouthwash, as desired.
- If dentures were removed, brush them with toothpaste or clean them with denture cleanser before replacing them in a clean mouth.
- Leave poor-fitting dentures out of the mouth to prevent mouth sores.
- Pat lips dry with a clean cloth and apply non-petroleum lip balm to prevent dryness. Reapply lip balm frequently during the day.

Toothettes may be easier to use than a toothbrush. They may be obtained from the Tidewell team. Follow the same instructions as for a toothbrush.

Ask the Tidewell nurse for special instructions for mouth care if your loved one is unconscious or unable to swallow or sit up.

When to call Tidewell Hospice

- If your loved one develops a sore throat or mouth sores.
- If white patches are noted on the tongue, gum line or roof of mouth.

MOVING THE PATIENT

When assisting a patient with movement, try using devices such as a draw sheet, mechanical lift or trapeze bar. These devices ensure self-care and patient safety. Ask the Tidewell nurse for more information on these devices.

Helping the patient get to a chair from the bed

Before starting, remember to take care of your back. Bend your knees, keep your back straight and reach as little as possible.

1. Explain to the patient what you are planning to do.
2. Move slowly.
3. Put the head of the bed up and have the patient turn toward the edge of the bed.
4. Swing the patient's legs down to the floor as you bring him or her to a sitting position. Wait a few moments to allow the patient to adjust to sitting up.
5. Have the chair placed at the head of the bed, facing the foot of the bed.
6. Face the patient and place your right foot between the patient's feet. Keep your back straight, reach under the patient's arms as they place their arms on your shoulder.

7. Hug the patient gently while raising the patient off the bed and pivot the patient toward the chair.
8. Lower the patient to the chair bending your knees and keeping your back straight.
9. Reverse the steps to return the patient to bed.

Assisting the patient from sitting to the standing position

1. Assist patient in moving to the edge of the bed or chair.
2. Stand directly in front of the sitting patient with your feet shoulder-width apart.
3. Tell the patient to place their hands on your shoulders.
4. Place your hands under patient's arms. Brace yourself by bending your knees and keeping your back straight.
5. Straighten yourself, gently raising the patient. Allow the patient to pull on your shoulders.
6. Do not let go unless you are sure the patient is stable.

Assisting the patient from sitting to the standing position

1. Assist patient in moving to the edge of the bed or chair.
2. Stand directly in front of the sitting patient with your feet shoulder-width apart.
3. Tell the patient to place their hands on your shoulders.
4. Place your hands under patient's arms. Brace yourself by bending your knees and keeping your back straight.

Helping the patient from the bed to a wheelchair or bedside commode

1. Place the wheelchair or bedside commode next to the head of the bed, facing the foot of the bed.
LOCK THE BRAKES
2. Refer to the directions for transferring the patient from sitting to standing.

If you are helping the patient get up or walk and find you can no longer manage the patient, ease the patient to the floor slowly. Make the patient as comfortable as possible before going for help.

Assisting the patient to walk

Before walking with the patient, have the patient stand for a few seconds to assess balance and avoid dizziness. Support the patient by placing one arm around the waist or holding the clothes at the waist.

1. Walk to the side of the patient.
2. If patient is using oxygen, tubing should be held to the side away from the feet.
3. Allow the patient to set the pace.
4. Observe the patient for the need to rest.

Walkers

Some patients may require a cane or walker to assist with safe mobility. A Tidewell team member will instruct you about adjusting and using the walker or cane safely. Do not allow the patient to use a walker or cane alone until he or she has been shown how to properly use the equipment. If the patient feels unsteady, the walker or cane should not be used unless someone else is in the home.

Helpful hints for use of small equipment (wheelchairs and walkers)

- Clean the equipment with soap and water. Towel dry the equipment completely before patient use.
- Using a blue pad or pillow case on the seat of a wheelchair may prevent the need for frequent cleaning of seat pads.
- Contact a Tidewell team member if the equipment is broken or cracked.

Using a shower chair or bath bench

A shower chair or bath bench can be used for patients who are walking with assistance and would prefer to use the shower. These devices are made of plastic and metal and usually fit in a standard tub or shower. A Tidewell team member will provide instruction regarding the specific equipment for use in your bathroom.

Helpful hints when using shower chairs and bath benches:

- Never allow the patient to use the shower chair or bath bench while home alone.
- Remove all throw rugs from the bathroom for safety.
- Clean the bench or chair with bathroom cleaner, making sure all soap is rinsed off to prevent slippery surfaces.

Turning a patient from side to side in bed

1. To help decrease fear and anxiety, always begin by telling the patient what you are going to do before starting the procedure or process.
2. If the patient is in a hospital bed, raise the side rail on the side the patient is going to be turned toward.
3. Move the patient closer to you as you stand at the side of the bed.
4. Move the pillow toward the raised side rail, providing support for the head.
5. Bend the knee that is on top.
6. With your hand on the closest shoulder and hip, turn the patient toward the side rail.
7. Firmly place a pillow behind the patient's back for support.
8. Place other small pillows or folded towels between the knees and ankles.
9. Adjust the shoulders, pulling the bottom shoulder slightly out. Add a pillow under the arm.
10. Adjust head pillow for comfort. Ask if the patient feels comfortable. Put up both side rails, cover patient for warmth.
11. It is not unusual for the patient to moan at times during the turning process. Once the patient has completed the turn, the comfort level will return.

Placing a lift sheet

A lift sheet is useful when a patient can no longer help themselves move. The lift sheet is a flat sheet or extra-large bath towel placed under the patient that allows you to move the person without directly pulling on them.

1. With the patient lying on their side, place a lengthwise-folded sheet along the back, from the shoulders to the thighs. Tuck at least half of the sheet under the patient.
2. Putting the side rail up on the side you have been working on, move to the other side, put this side rail down and assist patient to roll over the folds of the lift sheet.
3. Straighten out the sheet, smoothing the wrinkles. Position the patient as desired.

Using a lift sheet

- To turn the patient side-to-side, remove any pillows used to support the back and legs. Using the lift sheet, shift the patient toward you, then turn patient away from you. Tuck a full-size pillow behind the back. Smooth out the sheets. Position other small pillows or folded sheets between the knees and ankles. Be sure to re-adjust the head pillow and ask the patient if he/she is comfortable.
- To lift a patient to the top of the bed, use another person and place one of you on each side. Each person should grab an edge of the sheet around the shoulder and the edge by the hips. On the count of three, lift and move the patient up to the head of the bed.

Changing sheets with a patient in the bed

The best time to change the bed is just after a bath, although you should periodically check for crumbs, creases or moisture as these can make the bed uncomfortable and contribute to skin breakdown.

- Leave one pillow on the bed, placed under the head. Keep the body covered loosely with a sheet or light blanket.
- If changing in an electric bed, raise it to a height that is comfortable for you to work at the bedside.
- Help your loved one roll to one side of the bed. If in an electric bed, be sure the rail on the side the patient is rolling toward is up.
- Work from the side with the loved one's back facing you. Loosen all bedding on that side and roll the bottom sheet to the middle of the bed.
- Place a fresh sheet on the bed, with the middle of the sheet in the middle of the bed. If you are using a pull sheet or incontinence pad, place those in the same way.
- Tuck in the side, top and bottom of the sheet on the side you are working on, then roll the rest of the bedding to the middle of the bed, tucking the roll under the back and legs.
- Have the patient roll toward you over the folded linen and onto the clean side of the bed. If there's a side rail, pull it up before moving to the other side of the bed.
- Pull out the dirty linen.
- Unroll the clean bedding and tuck in side, top and bottom of sheet on the second side.
- Position the patient as the nurse has taught you, covering with a clean top sheet or blanket if loved one desires. If the loved one prefers to be on his or her side, remember to use pillows between the knees. If the loved one prefers to be on his or her back, consider placing a pillow under the lower calves to elevate the heels.

Putting the patient on the bedpan

1. Put on gloves. Powder the bedpan to avoid any injury to the patient's skin.
2. With the opposite side bed rail up, roll the patient to that side.
3. Place the bedpan squarely on the buttocks.
4. Roll the patient back over on top on the pan. Check between the legs to make sure the patient is properly seated on the bedpan.
5. Raise the head of the bed.
6. Put up the other side rail. Stay within calling range or leave a bell nearby.
7. When the patient is done, roll them off the pan. Be careful not to let the pan tip.
8. Help cleanse the patient and pat dry.
9. Dispose of the waste in the toilet, clean out the bedpan.
10. Always be sure to check the comfort of the patient and make sure the bed rails are in the up position.

NAUSEA AND VOMITING

Nausea can occur even when a person is not thinking about food and vomiting can occur even when there is no food in the stomach. Nausea and vomiting can especially be a problem the first few days after starting a new pain medication. Frequent vomiting can cause patients to inhale food particles or become dehydrated so ask the Tidewell nurse for help if you experience nausea or vomiting.

- If the nausea occurs only between meals, give the patient frequent, small meals, snacks at bedtime and leave food within easy reach.
- Find foods the patient likes; many patients don't like the taste of red meat and meat broth. Serve other protein sources.
- Offer clear liquids served cold and have the patient sip them slowly. (Clear liquids include any fluids you can see through when contained in a glass.)
- Be sure that the Tidewell nurse is aware of the problem. Medications can be ordered to relieve these symptoms.

- Have the patient rest comfortably in a quiet place.
- Provide distraction, such as soft music, a favorite television program or stay and keep the patient company.
- Provide good mouth care.

If the patient is vomiting

- If the patient is bedridden, be sure he or she is moved to his or her side so the vomit will not be inhaled.
- Provide liquids in the form of ice chips or frozen juice chips.
- Give sips of ginger ale or peppermint tea.
- Keep a record of how often and how much the patient vomits.

What not to do

- Do not force foods or fluids on a patient who is nauseated or vomiting.
- Do not allow the patient to lie flat on his or her back.
- If the patient is vomiting frequently, do not allow the patient to eat for four to eight hours, then start feeding again with clear liquids.

When to call Tidewell Hospice

- If you are concerned that some of the vomited material has been inhaled.
- If the vomiting occurs more than three times an hour for three or more hours.
- If any blood or material that looks like coffee grounds appears in the vomit.
- If the patient is unable to take his or her medications.
- If the patient feels unusually weak or dizzy.
- If the patient loses consciousness.

NUTRITION

There are many reasons that appetite and food intake can decrease. Although an encouraging, gentle approach may help, we must respect the individual's choice. Tidewell Hospice recommends you do not force the person to eat or constantly remind him or her of the decreased appetite.

Other ways to encourage eating include serving meals in a relaxed, comfortable and bright atmosphere. When feasible, eat in the room with your loved one. Remove unpleasant odors and do not schedule unpleasant procedures around meal time.

How to help

- Offer mouth care before and after meals to freshen up the mouth and stimulate taste buds.
- Make the most of breakfast as appetite tends to decrease as the day goes on.
- Offer pain medications on a schedule that reduces discomfort before and during meals. For example, offer pain medication 30 minutes before meal time.
- Keep the head of the bed elevated to promote digestion for 15-30 minutes after meals.
- Adjust the diet if your loved one can no longer wear dentures. Soft foods or small, bite-sized portions of food may be softened with sauces or gravy.
- Inform the Tidewell nurse if nausea is a problem. The nurse can ask the doctor about ordering a medication to reduce nausea.
- Offer small, frequent meals and leave a high-protein snack or drink at the bedside. Tidewell can provide information and recipes for high-protein supplements.
- Consider patient requests e.g., if the patient requests ice cream for breakfast, be open to this.
- If the patient is lying flat, elevate the head of the bed before beginning the meal.

When to call Tidewell Hospice

- Your loved one is unable to swallow.
- Reports pain when swallowing.
- Reports nausea or vomiting.

Super Shake Recipe

INGREDIENTS:

Base (use ½ to 1 cup of one of the following)

- Whole milk
- Double-strength milk*
- Supplement of choice, such as Boost® or Ensure®
- Half-and-half

Frozen flavor addition (use ½ to 1 cup of one of the following)

- Ice cream, for extra calories use a brand that has 300 calories per ½- cup serving like Häagen-Dazs®
- Sherbet
- Fruit sorbet (lactose-free)
- Tofutti® (lactose-free) or “so Delicious” (dairy-free, lactose-free)
- Frozen juice concentrate or frozen fruit (lactose-free)

Extra protein and calorie addition (use 2 to 4 tablespoons of one of the following)

- Pasteurized liquid egg or egg substitute
- Powdered whole milk
- Egg and or whey protein powder
- Peanut butter
- Double-strength milk*

Flavoring and calorie additions (use ½ to 1 teaspoon of one of the following)

- Vanilla extract or other essence
- Chocolate syrup (1 to 2 tablespoons)
- Instant coffee granules

- Cocoa mix
- Cinnamon or nutmeg

Place all ingredients in a blender and blend well. Consider using a favorite garnish to give it a “soda-fountain” appeal: maraschino cherry, shaved chocolate, whipping cream, and/or a cookie wafer. Yield: One beverage.

Double Strength Milk Recipe

INGREDIENTS:

1½ cup whole milk powder

2 cups whole milk

Blend milk powder with milk in a blender until well mixed.

Refrigerate. This recipe may be doubled.

Signature Smoothie

INGREDIENTS:

½ cup orange, pineapple, apple, cranberry, or other favorite juice

Fresh fruit, use one or mix a few of ½ banana, 1 cup berries, 1 medium peach, ¾ cup pineapple, 1 medium peeled orange, or 1 cup any exotic fruit

½ cup or to taste of ice cream, frozen yogurt, sherbet, fruit sorbet (for lactose-free use Tofutti® or “so Delicious”)

Make sure all ingredients are golf ball size or smaller, put into blender and blend on high for 30 seconds. Stop and free any chunks on the bottom and blend 30 seconds more.

Frozen Smoothie Flavoring and Supplements (optional) Protein supplements (select one)

¾ cup yogurt made with whole milk

¾ cup soy milk

¾ cup milk

1 serving protein powder

2 tablespoons non-fat dry milk

Blend well.

Frozen Smoothie Flavoring and Supplements (optional) Protein supplements (select one)

$\frac{3}{4}$ cup YoBaby® yogurt or other yogurt made with whole milk

$\frac{3}{4}$ cup soy milk

$\frac{3}{4}$ cup milk

1 serving protein powder

2 tablespoons non-fat dry milk

2 tablespoons instant breakfast mix (Carnation Instant Breakfast®)

Flavorings, fiber and other calorie boosters (select up to two)

1-2 tablespoons peanut butter

1-2 tablespoons ground peanuts, walnuts or almonds

1 tablespoon canola oil

1-2 tablespoons chocolate syrup

*Double-strength milk: 1 $\frac{1}{3}$ cups whole milk powder, 2 cups whole milk. Blend milk powder with milk in a blender until well mixed. Refrigerate. The recipe may be doubled.

PAIN MANAGEMENT

Not all patients experience pain, but those who do can often find relief of that pain and increased quality of life.

What is pain?

Pain is an uncomfortable feeling that can affect every aspect of someone's life. Pain can be mild and nagging or severe and disabling. The patient is an important part of the pain management team, and he or she will be asked to keep the Tidewell care team informed of:

- Their level of pain.
- If the pain is not being controlled.
- Any personal, ethical, spiritual or cultural issues they may have regarding pain management.

There are many types of pain and pain medications.

For mild to moderate pain, over-the-counter medications or prescription medicine may be ordered.

For moderate to severe pain, the nurse will obtain orders from the doctor for medication.

There are times when more than one type of medicine may be needed to treat the pain. It is important for the patient to describe his or her pain the best he or she can to help the nurse identify the type of pain.

For example, nerve pain may be described as tingling or burning or pain caused by swelling may be described as pressure. Some words people may use to describe pain are aching, burning, stabbing, sharp, spasm, throbbing, tingling, shooting, gnawing, pressure, tight.

Taking pain medication

Most pain medication is taken by mouth. If a patient who has difficulty swallowing and cannot take a tablet or liquid, ask the doctor for other options such as:

- Suppositories
- Concentrated liquids taken under the tongue
- Skin patch
- Intravenous or subcutaneous infusion

Some medications are long-acting, which means they are taken regularly and their effects last for a long period of time. Sometimes the patient experiences pain in spite of a long-acting pain medicine. The nurse may refer to this as “breakthrough” pain. The doctor may order a shorter-acting medication to take care of breakthrough pain.

Possible side effects of pain medication

Many medicines have side effects, but not all people experience them. Some of the most common side effects of pain medication are:

- Constipation
- Drowsiness
- Nausea and vomiting

It is important to inform the Tidewell nurse if the patient experiences any of these side effects. Additional medication may be needed to control side effects.

When to take pain medication

To help the pain medicine be most effective, the patient should:

- Take the medicine regularly, as ordered. Taking medicine regularly will help keep pain under control. Never skip a dose and never wait for the pain to get worse before taking medicine.
- If certain activities make the pain worse, the patient may need extra doses before doing them. Always check with the nurse to be sure the medication is being taken as ordered.
- Once the patient is in pain, it is harder to get the pain under control.

The goal of pain medication is to prevent or control the pain. If the medication or treatment does not work, changes can be made. It is important to keep a record of medication the patient has taken. The nurse will review the record and make adjustments if necessary.

Non-drug treatment of pain

- Aromatherapy
- Breathing and relaxation
- Distraction
- Hot/cold packs
- Imagery
- Massage, pressure, vibration
- Music
- Rest

Why pain should be controlled

Pain can keep someone from being active, from sleeping well, from eating and from enjoying family and friends. Pain can also make someone feel anxious or depressed. All pain can and should be controlled to the greatest possible extent, in order to achieve a maximum quality of life.

The key to getting the best pain relief is talking with the doctor and Tidewell nurse. Answering the following questions will help initiate the appropriate treatment:

- Where is the pain?
- What does it feel like (ache, throb, burn, tingle)?

- How bad is the pain (rate 0 to 10 with 0 =no pain and 10 =worst pain)?
- What makes the pain better or worse?
- Is the current treatment working?
- What is the goal for pain control?

Ask your Tidewell nurse for a Pain Management Log to keep track of pain.

Please talk to the Tidewell team members about pain; they are committed to keeping the patient comfortable.

PAIN MEDICATION SIDE EFFECTS

Understanding the side effects of opioid pain medications is essential for helping you be confident and comfortable with providing these medications to your loved one. The good news is that not everyone has side effects from pain medications. In fact, most side effects can be prevented. The most common side effects are usually drowsiness, constipation, nausea and vomiting. Some of the mild ones such as nausea, itching or drowsiness, often go away after a few days as the body adjusts to the medicine.

Drowsiness

Pain medications may cause drowsiness when the person first starts taking them, but this usually goes away after a few days. If the pain has kept him or her from sleeping, the person may sleep more for a few days after starting the new medication while “catching up” on sleep. Drowsiness also lessens as the body gets used to the medicine. Take extra care and safety precautions when you first start giving pain medication. Do not let the patient do anything that requires being alert until you know how the medicine affects him or her. If the medication is not relieving the pain, the pain itself may be tiring the patient out.

Constipation

Pain medications cause constipation in most people. This is because pain medications slows the movement of stool through the intestinal tract, which allows more time for water to be absorbed by the body and the stool to become hard. The body does not develop a tolerance to constipation from opioids, but constipation can often be prevented or controlled. It’s best to start a laxative, stool softener or other treatments to keep the bowels moving when the patient first starts taking pain medication. The Tidewell nurse should provide you with information on stool softeners and laxatives, including how often and how much the patient should take.

Nausea and Vomiting

Nausea and vomiting caused by pain medications usually goes away after a few days of taking the medicine. If your loved one has more nausea when up or walking around but not when lying down, have him or her stay in bed for an hour or so after you take the pain medicine. This type of nausea is like motion sickness. If the pain itself is causing the nausea, using medication to relieve the pain usually makes the nausea go away. Medicines that relieve nausea can be prescribed if needed. Constipation may also worsen nausea. Some people think they are allergic to pain medications if they have nausea after taking them. Nausea and vomiting alone usually are not allergic reactions.

When to call Tidewell Hospice

- If the medication is not relieving pain.
- If the patient is having any side effects and needs help with management of those side effects.
- The patient cannot hold down food or liquids for a full day.
- When nausea lasts more than a few days.
- If the patient feels too sleepy for normal activities after taking the medication for a few days.
- If the patient is taking other medications that could also cause drowsiness.
- Before taking any additional stool softeners or laxatives.
- If the patient still feels constipated after trying all the above measures or if he or she has not had a bowel movement for two days or more.

SEIZURES

Seizures may appear as facial twitches, tremors in one or more areas of the body or a convulsion of the entire body. Seizures generally last a few minutes or less. A seizure cannot be stopped once it has started, but a patient can be helped during a seizure.

How to help

- Keep calm
- Protect the patient from injury by:
 - o Easing patient to the floor or bed if patient is standing.
 - o Padding the bed rails (use towels, blankets, pillows).
 - o Removing sharp or hard objects near the patient.

- Help the patient with breathing by:
 - o Turning head to side if secretions are present.
 - o Loosening constricting clothing such as belts or ties.
 - o Placing something soft under the patient's head.
- Call Tidewell.
- Allow patient to rest after seizure has subsided.

What not to do

- Force anything between the teeth.
- Put your fingers in the patient's mouth.
- Interfere with the patient's movements unless it's essential for personal safety.

SKIN CARE AND PRESSURE INJURY PREVENTION

When parts of the body don't receive enough oxygen, skin problems or pressure sores develop and the tissue in that area dies.

Being bedridden or in a wheelchair for long periods of time puts pressure on the same places, making these areas more likely to develop skin breakdowns. These areas can be made worse when the sheets rub against the skin, if patient is pulled up in the bed or chair, or if the patient is left in urine or feces too long.

How to help

- In bed, change patient's position every two hours.
- In chair, change patient's position every 15-30 minutes.
- Provide incontinence care every two hours and when soiled.
- Relieve pressure by using pillows.
- Apply barrier cream as ordered.
- Report skin changes, pain, redness and new wounds to Tidewell.
- Change wound dressing as needed.

Check the patient's skin for reddened areas each day during the bath. If the pressure areas become red, tell the Tidewell nurse. Even with the best care, skin breakdown may occur. The Tidewell care team can suggest ways to treat pressure sores and promote skin healing.

When to call Tidewell

- The skin is cracked, blistered or broken.
- The sore smells foul.
- There is drainage from the sore.

SWALLOWING PROBLEMS

Swallowing problems may occur with certain diseases or a decline in condition. Inform the nurse if you notice your loved one has problems swallowing (e.g., trouble getting food or liquid down without gagging, coughing, spitting or pain when trying to swallow).

How to help

- Change diet to liquid or very soft foods.
- Puree soups and stews in a blender before serving.
- Add gravy or sauce to dry foods.
- Sit in a straight chair at a table, or raise head of bed when eating.
- Drinking carbonated beverages with food may help.

What not to do

- Do not force a person to eat if he or she is having difficulty swallowing.
- Avoid foods that require a lot of chewing, such as meats, chewy candy, raw whole vegetables or fruits.
- Avoid hot, spicy foods or liquids.
- Avoid alcohol, citrus fruits or drinks, crackers, nuts or chips.

Certain foods or commercially prepared thickening agents can help thicken liquids for easier swallowing, such as gelatin, tapioca, flour or cornstarch, pureed vegetables and mashed potatoes, dry infant cereal,

instant potatoes and commercial thickeners.

When to call Tidewell Hospice

- If the patient is coughing, choking or has a sore throat.

URINE ELIMINATION

Some patients are not able to control urination. In others, the urine can't move through the body the way it should.

If either of these conditions is present, one of several options may be considered including adult incontinence briefs, external catheters (male patients only) and the placement of a catheter (tube) into the bladder to drain the urine. This procedure is only done at the direction of the doctor and after talking to the patient and family. If everyone agrees that a catheter is needed, the nurse will place the catheter and teach the patient and family on its function and care.

How to help

- Offer all types of fluids to the patient. (Tea, coffee and cranberry juice have a diuretic effect, but include all types of liquids.)
- Help start urine flowing by running water, pouring warm water over hands and genitals, having patient drink a glass of water or gently massaging the lower abdomen over the bladder.

What not to do

- Discontinue giving the patient fluids if he or she does not urinate after 24 hours.
- Do not force the patient to drink if he or she feels unable to do so.

When to call Tidewell Hospice

- The patient does not produce urine for more than 24 hours.
- The patient's abdomen appears bloated.
- The patient complains of pain in the lower abdomen or in the mid back.

URINARY CATHETER CARE

What is a urinary catheter?

A catheter is a tube with an inflatable balloon at the end. The nurse or doctor inserts the tube into the bladder and inflates the tiny balloon with a small amount of water to hold the tube in place in the bladder. After the nurse connects the tube to a drainage bag, urine will be seen in the tube as it drains into the bag.

Things to remember about urinary catheters

- Always wash your hands before and after working with the catheter drainage bag.
- Check the drainage tubing for any kinks and make sure the drainage bag is below the level of the patient to encourage draining.
- Check for any leaking around where the catheter enters the body and tell the nurse if any leakage is seen.
- Empty the drainage bag at least once a day.
- Empty urine from the bag into an empty plastic milk or juice bottle, cleaning the bottle between each use.

Things needed for catheter care

- Warm water in a basin.
- Washcloth and towel.
- Tape or clean catheter strap (as instructed by nurse).
- Soap.

Cleaning the catheter

Begin by washing the area around the catheter entrance gently but thoroughly. Rinse the area with warm water and then pat dry.

- Explain to the patient what you are doing.
- Wash your hands.

- Clean the area where the catheter enters the body with a washcloth, soap and water. Repeat as necessary, rinsing well.
- Dry gently.
- If the patient is active, help the patient with the tubing and drainage bag, using care not to pull the catheter out. The Tidewell nurse can show how to secure the catheter when moving.
- Be sure tubing is straight and free of kinks so urine drains continuously.
- Always place the drainage bag below the level of the bladder to aid in draining.
- Wash your hands.

When to call Tidewell Hospice

- Signs of redness or irritation of the skin are seen where the catheter enters the body.
- Changes in color or odor of urine.
- No urine in the bag after eight hours.

Irrigating the Catheter

If a catheter becomes blocked, irrigating the catheter can restore the flow of urine.

Catheter blockage should be suspected if urine flow has stopped and there are no kinks in the lines and the collection bag is below the level of the patient.

* * * PLEASE CALL THE NURSE BEFORE ATTEMPTING TO IRRIGATE * * *

Supplies needed to irrigate the catheter:

- Irrigation tray and syringe (provided by Tidewell)
- Sterile saline solution
- Alcohol wipes
- Waterproof bed pad

How to irrigate the catheter

- Always call the nurse prior to the first time you plan to irrigate.
- Wash your hands well.
- Place a waterproof bed pad under the work area to protect the bed linens from any spilled urine.
- Pour sterile saline into the irrigating container (about ½ cup).
- Remove the cover tip of the syringe remembering not to touch the sterile tip of the syringe. Keep the cap nearby.
- Separate the tubing from the collection bag.
- Remove the cap from the syringe and fill syringe ½ to ¾ full with sterile saline from the container. Push the tip of the syringe into the catheter until it fits snugly.
- Gently push the solution into the catheter. If you meet a lot of resistance, stop and reconnect the tubing to the bag and notify the nurse.
- If the solution goes in easily (as it should), disconnect the syringe and let the catheter drain into the irrigation tray container.
- Replace the cap on the syringe and discard.
- Reconnect the catheter to the drainage bag and tubing.
- Dispose of urine and any unused saline into the toilet.
- Wash your hands.

SAFE MEDICATION MANAGEMENT

Medications should always be stored properly in a safe and secure location, away from children, pets or unauthorized persons. Never share medications. Medications are prescribed for legal use only by the patient. The patient and/or family are responsible for the security of prescription medications in a home setting. Storage of medications in their originally labeled containers is encouraged whenever possible to avoid confusion regarding medication directions or identification of medications. Please contact the Tidewell nurse with any questions or concerns regarding medication storage, security or administration.

LEAVING THE RESIDENCE

There may be a time when it is necessary your loved one to no longer receive care in the home. For example, sometimes the best choice for the circumstance is for your loved one to receive care at a Tidewell Hospice House.

In preparation for leaving your residence, below is a list of suggested items that you may want to take with you. This is just a guide and may not include items unique to your specific situation. Please check with the Tidewell nurse for further information and advice.

- Personal items: toothbrush, toothpaste, deodorant, shaving supplies, toiletries.
- Non-medicine items: lip balm, powder, body spray.
- Your nurse will help you determine any medications that you need to bring.
- Special pictures, books, and personal items.
- Favorite comfort items such as pillows and blankets.
- Comfortable clothing, pajamas, robe, appropriate slip-proof footwear.
- This Patient and Family Resource Guide.
- PLEASE LEAVE ANY VALUABLES AT HOME.

WHAT TO EXPECT AT END OF LIFE

FOOD AND FLUIDS AT THE END OF LIFE

Food is nourishment for the body and soul. It is also one of the ways we show love and provide comfort to loved ones.

During times of great distress, families often turn to familiar traditions for providing comfort and expressing love, and these traditions often involve food. At end of life, however, many people no longer desire food or drink. When your loved one stops eating and drinking, you may wonder how to show him or her you care. Refusing food and drink is one of the symptoms of the natural dying process and not its cause. Side effects of dehydration include thirst and dry mouth, both of which can be alleviated by providing frequent and thorough mouth care. This is an opportunity for you to express that you care in a new way.

For the majority of people, food and fluids do not increase the quality or quantity of life. In fact, forcing someone to eat or drink at the end of life may cause discomfort, including shortness of breath, bloating, gas, nausea, vomiting or diarrhea. Additionally, the muscles used to chew and swallow become weak at the end of life, causing difficulty swallowing and possibly choking.

If you have any questions about your loved one's food and fluid intake, contact your Tidewell nurse. As the caregiver, there are ways you can provide nutritional comfort to your loved one.

How to help

- Let your loved one decide whether or not to eat or drink.
- Offer small meals or snacks.
- Eat with your loved one.
- Offer a balance of solid food and liquids.
- Offer soft food items to decrease the work of chewing and swallowing.
- Offer small chips of ice, frozen juice or popsicles; many people find these refreshing.
- Place your loved one in an upright position to eat or drink.
- Provide mouth care before and after each meal and snack.
- Avoid heavy and/or fried foods.
- Avoid foods with strong odors.

Discuss any questions or concerns you have about your loved one's change in eating or drinking habits with your Tidewell team. The "Nutrition" section of the Patient and Family Resource Guide has recipes for easy-to-make shakes and smoothies.

When to contact Tidewell Hospice

- Your loved one stops eating and drinking altogether for more than 24-48 hours.
- If you think your loved one has choked on food or liquid.

AS THE TIME OF DEATH NEARS

Tidewell Hospice realizes that in the final stage of your loved one's terminal illness, your anxiety about the unknown brings many questions to mind. This section is designed to assist you with recognizing signs that appear in most people as the body systems slow down and finally stop functioning, what members of the Tidewell team may refer to as transitioning. This section also offers suggestions for how you can support your loved one during this time.

First, be aware that the dying trajectory is an individualized process. For some, these signs begin to appear a few hours before death, while for others they may appear a few days or weeks before. Common events in the dying process occur in no particular order and may not occur at all. By knowing what to expect, Tidewell hopes that you will become more comfortable as you and your loved one experience this time together. You know your loved one better than anyone and can respond best to his or her personal comfort needs. Sometimes this may be as simple as sitting or lying with your loved one and giving the comforting assurance that you are there. Tidewell is there to assist as you develop ways that can help your loved one accomplish this transition with support, understanding and ease. This is the greatest gift of love you have to offer during this time.

When a person enters the final stage of their life, two different things are happening. On the physical side, the body begins the final process of slowing and shutting down. Physical changes are a normal part of this process, though they vary from person to person and are impacted by specific disease processes.

On the emotional/spiritual side, a dying person often begins to let go of their environment and relationships. It is a natural way in which many people begin to transition. Your support, understanding and encouragement is helpful during this time. If you feel your loved one is having a difficult time emotionally or spiritually during this transition, you may want to seek support and more specific guidance from your Tidewell team.

Not all of the signs and symptoms presented here will occur with every person. These pages serve as a simple guide to assist you as you care for your loved one. Again, it is important to remember that the dying process is as unique as life itself. Each person needs to do things in their own way. This is not the time to change lifelong habits or dictate an approach to death, but a time to give your full acceptance, support, and comfort.

Among the dying there is a shift from a mental processing of death to a true comprehension and belief in one's own mortality. Unfortunately, this understanding and the work of processing it may not always be shared by others so be open to your loved one's expression of it.

The following signs and symptoms typically begin one to three months before death occurs. The actual dying process, how the body prepares itself for the final stage of life, often begins in the two weeks prior to death.

As these last days pass, loved ones and friends often ask what they need to do during this time. Besides keeping the patient clean and comfortable, some families sit by the bedside to share stories, read aloud, sing special songs or play favorite music. Even if your loved one does not seem to hear or recognize the people around them, we know that our sense of hearing lingers the longest. For this reason you can assume that your loved one is likely hearing what is being said.

Touch is also important. You have the best personal knowledge of what your loved one might find comforting. For some, gently rubbing lotion on the back, arms and legs can be soothing. Sometimes it is enough to just hold hands so that your loved one knows that they are not alone. There are no rules: family and friends usually do just the right thing by doing what comes naturally. Special memories can be made and shared during this time.

ONE TO THREE MONTHS PRIOR TO DEATH

Fluid and food decrease: Food is fuel for the body. It is the means by which people keep their bodies going, moving and alive. We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. For family and loved ones this may be one of the hardest concepts to accept. Your loved one may have a decrease in appetite and thirst, wanting little or no food or fluid. The body naturally begins to conserve the energy which is used for these tasks. Do not try to force food or drink or try to trick your loved one into eating or drinking something he or she does not want. There is a gradual decrease in eating habits. Sense of taste is often altered and cravings may come and go. Liquids are preferred to solids. You may hear your loved one say: "I just don't feel like eating."

Meats are the first to go, followed by vegetables and other hard to digest foods until even soft foods are no longer eaten. Normal hydration is often not possible. We have found that the dying process is more peaceful in a state of dehydration than a state of fluid overload. Small chips of ice, frozen juices and Popsicles® may be refreshing in the mouth. Be careful of problems with swallowing and do not force fluids if the person coughs soon after swallowing. The person's body lets him or her know when it no longer desires or can tolerate food or liquids. Dehydration does not make the patient uncomfortable.

The Tidewell nurse may suggest mouth swabs and frequent mouth care to provide moisture to the mouth. At this point, it is okay not to take food or fluids.

Decreased socialization/withdrawal: It is not uncommon for your loved one to experience a period of withdrawal or separation. As your loved one processes the impact of "Yes, I am dying," a person begins to withdraw from the world. This may signal the beginning of the emotional pulling away from the environment. Your loved one may begin to show no interest in newspapers or television; this may include a loss of desire for visits from neighbors or friends. There may even be a feeling that your loved one does not wish to be a burden to others and excluding the people they love the most.

With this withdrawal may come less of a need to communicate with others. Your loved one may want to be alone, with just one other person or with a very few close people. It is natural to not feel like socializing when weak and tired. Reassure your loved one it is okay to sleep and rest. Honor the need for quiet time, calming and intimate surroundings.

You may wish to sit with your loved one and hold their hand. Speak directly, softly and naturally, as you normally would.

Sleeping: Your loved one may spend an increasing amount of time sleeping. A morning nap is added to the usual afternoon nap and they may appear to be sleeping all the time and difficult to arouse. This is a normal change due in part to changes in the functioning of the body. Plan to spend time together when they are most alert. At this point, "being with" is more important than "doing for."

ONE TO THREE WEEKS PRIOR TO DEATH

Your loved one may begin to appear restless, pulling at the bed linens or clothing. This is common and is due, in part, to the decrease in circulation to the brain and other changes in the body. Do not be alarmed or try to interfere or restrain such motions. Try to create a calming environment by speaking in a quiet, natural way; lightly massaging the hand or forehead; or playing soothing music. You can ask the members of your Tidewell team for other suggestions.

Your loved one may also seem confused about time, place and the people present. It may help to identify yourself by name before you speak. Speak softly, clearly and truthfully when you need to say something important to comfort your loved one, such as “It’s time to take your medication so you won’t begin to hurt.”

Physical Changes

Urine decrease: As a natural part of the dying process, your loved one’s urine output will decrease and may become tea-colored at this time. This is referred to as concentrated urine and is caused by the decrease in fluid intake or decrease in kidney function.

Incontinence: Your loved one may begin to lose control of the bladder and/or bowels as the muscles in that area begin to relax. Protecting the bed and keeping your loved one clean, dry and comfortable is important. For guidance please feel free to discuss this with your Tidewell nurse.

Heart beat: You may notice changes in your loved one’s pulse, either increasing from a normal of 80 beats per minute to upwards of 150, or decreasing significantly.

Body temperature: Your loved one may fluctuate between experiencing fever and cold.

Breathing pattern change: You may notice a change in your loved one’s breathing pattern. They may begin breathing irregularly with shallow breaths, or even experience periods of no breaths for 5 to 30 seconds, followed by a deep breath. The person may also have periods of rapid, shallow panting-type breathing. Sometimes there is a moaning like sound when the person breathes out. This is not a sign of distress, but rather the sound of air passing over relaxed vocal cords. These breathing patterns are common. Elevating your loved one’s head and/or turning onto the side may bring comfort. Hold your loved one’s hand lightly and speak gently and reassuringly.

Congestion: Your loved one may develop gurgling sounds coming from the chest, like a rattle. Sometimes these sounds become very loud and can be distressing to hear. If you watch your loved one closely you will notice that they are usually unaware at this point. It is probably harder for you to hear and watch than it is on your loved one. Suctioning the secretions that are causing this sound is usually ineffective and can be hard on the patient. It may help to raise the head of the bed to keep the secretions pooling low and prevent gagging. Elevating the head and/or turning onto the side may bring comfort. Again, lightly hold your loved one’s hand and speak gently and reassuringly. Notify the Tidewell nurse if this begins.

Color changes: Your loved one's arms and legs may become cold, hot or discolored. There may be increased perspiration, often making the skin feel damp. The underside of your loved one's body may become discolored as circulation decreases. This is normal. Irregular body temperatures can occur, so keep your loved one warm if they appear cold but do not use an electric blanket. If they continually removes covers, then just use a light sheet.

ONE TO TWO DAYS TO HOURS PRIOR TO DEATH

During this time, the nurse or hospice team may tell you your loved one is actively dying. Some people experience a surge of energy during this time. Your loved one may talk clearly and be alert when before there had been disorientation. Your loved one may ask for a favorite meal when they have not eaten for days. Your loved one may sit in the living room with relatives and visit after not wanting to be with anyone for quite a while. This surge of energy is not always as noticeable as the above examples, but in hindsight, the change can usually be easily recognized. Embrace this opportunity to create a lasting positive memory.

Physical Changes

One to two weeks: The signs that were present earlier become more intense as death approaches.

Restlessness: Restless behavior can increase due to lack of oxygen or accumulation of waste products in the blood.

Breathing patterns: The rhythm of breathing becomes slower and more irregular. Breathing often stops for 10 to 15 or up to 45 seconds before resuming again.

Congestion: Respiratory noises related to congestion can become very loud. Positioning your loved one on one side or the other may reduce the congestion.

Eyes: Your loved one's eyes may be open or semi-open, but not seeing. There may be a glassy look to them, often tearing.

Hands and feet: The extremities will likely now become purplish. The knees, ankles and elbows, as well as the underside of the arms, legs, back and buttocks may become mottled.

Responsiveness: Your loved one will most likely become unresponsive (unable to respond to the environment) sometime prior to death.

AT THE TIME OF DEATH

At the time of death, breathing stops, as does the heart. You might feel like time stands still at that moment. Death is viewed by many as a reflective or sacred moment. It is a time to acknowledge that death can be filled with presence, connection, reflection, gratitude and love. Don't despair if you are not present at the time of death. Death can be an intimate moment of reflection whether you are present or not.

There is no need to call 9-1-1 unless there is a decision to start resuscitation. Resuscitation is hard on a patient with advanced illness and the decision to resuscitate or not should be made in light of the wishes of your loved one. Tidewell will honor your wishes and be with you.

At the time of death, please call the Tidewell number. A Tidewell nurse will be available to help you with next steps.

If family members or friends are present, share stories, say goodbye or offer a comforting touch. You may wish to call family members who are not present for support or to allow them an opportunity to say goodbye.

A shift occurs in your life when the care of your loved one stops, but the love you have shared does not. Please take a moment — or several moments — to take it all in. Crying is a natural response and an honest means of expressing your feelings when words will not come. Others may find that they are unable to cry. This is also a natural response and the tears may come later. Allow yourself to just be who you are — there is no right way to feel or express your feelings. Allow those thoughts and feelings to be a celebration or reflection of the relationship you have with your loved one.

SAFE MEDICATION DISPOSAL

Tidewell must comply with federal, state and local regulations regarding medication disposal during hospice care. It is important for patients and families to understand the hospice procedure for safe medication use and proper medication disposal. Disposal of unused medications may be required after a patient death or other circumstances in which the medications are no longer needed.

Proper medication disposal can reduce harm or risk associated with accidental ingestion, overdose or illegal abuse. The likelihood of harm is increased when drugs are not destroyed and remain in the home.

Your Tidewell nurse will work with you to make sure you understand the options for safe medication disposal. The nurse is required to record any medications disposed of or remaining in the residence after a patient death. A family member will be asked to witness this record. Tidewell staff is not allowed to transport medications in their vehicles for the purpose of disposal.

The Tidewell Hospice policy and procedure on Managing Safe Use and Disposal of Medication is provided below. Please review the policy as it offers specific information on safe and proper disposal of medications. At any time during hospice care you may contact a Tidewell nurse to discuss any questions or concerns regarding medication safe medication management and disposal.

Managing Safe Use and Disposal of Medications, Tidewell Policy 15.19

Effective Date: 1/3/2023

Purpose:

The purpose of the policy is to describe how to manage safe use and disposal of medications during hospice admission.

Policy:

Tidewell Hospice is committed to following best practice recommendations. Tidewell follows all applicable federal, state and local rules, regulations and guidance from Medicare and Medicaid programs. Tidewell's intent is to protect patients, families, and communities from harm, prevent illegal diversion of unused medications and reduce as much as possible the negative impact on the environment.

Procedure:

1. Upon admission to Tidewell Hospice, in compliance with Medicare Hospice Conditions of Participation, a copy of Tidewell's policy and procedure on Managing Safe Use and Disposal of Medications is given to and discussed with the patient, patient representative or family member.
2. Education on Tidewell's Managing Safe Use and Disposal of Medications Policy will occur on admission when medications are first ordered.
3. Documentation of the education will occur on admission in the Electronic Medical Record (EMR).
4. Safe medication use is the responsibility of the patient and family/caregivers. Patients are instructed to store medication properly in a safe and secure location away from access of children, pets or unauthorized persons. Patients are instructed to never share medications with anyone else as medications are prescribed for legal use only by the patient. The patient and/or family/caregivers are responsible for the appropriate security of prescription medications.

5. Medication disposal may be necessary upon patient death, discharge, medication dosage changes, discontinuation or if medications are no longer appropriate or necessary for patient care.
6. Medication lawfully prescribed and dispensed to the patient for the patient's use and treatment are the patient's property during the patient's life. A family member may take possession of patient property such as medications lawfully after a patient's death expressly, and only in order to dispose of the patient property or transfer them to a DEA Collector or law enforcement. It is not legal to transfer, share or sell medications with persons other than whom they were prescribed. The patient and/or family members are lawfully responsible and allowed to make decisions regarding the method and time of medication disposal.
7. A Tidewell nurse will be available to provide education and a demonstration on appropriate methods of medication disposal and to physically assist with medication disposal under the following circumstances:
 - a. The assistance is requested by a patient or adult family member
 - b. The patient is residing in a patient's or adult family member's home
 - c. The patient or adult family is present physically for the duration of the disposal and documentation.
8. Home Care and ALF Facilities (Allowing Hospice Medication Disposal) procedure will be followed below:
 - a. No Medication(s) Present
 - i. In the EMR death visit medication disposal section
 - a) Check "No medications" if no medications are present.
 - ii. A Medication Destruction Record (Clin057) does not need to be completed.
 - b. Inventory Completed and Destruction Completed
 - i. In the EMR death visit medication disposal section
 - a) Check "Inventory Completed and Destruction Completed," when medication is present, and an inventory of medication was completed.
 - b) Type the name of the destruction witness.
 - c) Check "Clin 057 will be transmitted to Compliance and Audit Department for inclusion in the patient chart."
 - ii. Complete a paper Medication Destruction Record (Clin057).

c. Inventory Completed and Destruction Declined

i. In the EMR death visit medication disposal section

- a) Check "Inventory Completed and Destruction Declined," when medication is present, inventory of medications was allowed **but** assistance with destruction was declined.
- b) Type the name of the witness declining destruction.
- c) Check "Educated family member/caregiver informed of safe methods of medication disposal and destruction" when education or demonstration is provided.
- d) Check "Clin 057 will be transmitted to Compliance and Audit Department for inclusion in the patient chart."

ii. Complete a paper Medication Destruction Record (Clin057)

d. Inventory and Destruction Declined

i. In the EMR death visit medication disposal section

- a) Check "Inventory and Destruction Declined" when medication(s) are present and **both** inventory and assistance with destruction of medications was declined.
- b) Type the name of the person(s) declining destruction assistance.
- c) Check "Educated Family member/caregiver informed of safe methods of medication disposal and destruction" when education or demonstration is provided.
- d) Check "Clin 057 will be transmitted to Compliance and Audit Department for inclusion in the patient chart."

ii. Complete a paper Medication Destruction Record (Clin057)

9. LTC and ALF Facilities (Not Allowing Hospice Medication Disposal) procedure will be followed below:

- i. In compliance with long term care facility and selected ALF facilities rules and regulations, patient medication destruction will be according to the facility policy and procedure.
- ii. In the EMR death visit medication disposal section
 - a) Check in the EMR "Medications to be disposed of per facility policy."
- iii. A Medication Destruction Record (Clin057) does not need to be completed.

10. Hospice House procedure will be followed below:

- i. A Medication Destruction Record (Clin057) documenting all **patient-specific** medication disposal will be completed and forwarded to Compliance and Audit Department for inclusion in the EMR.
- ii. In addition, for patient specific Schedule 2, 3, 4 or 5 controlled substances the Patient Specific Perpetual Inventory Log HH002 will already be in use and must also contain the following documentation:
 - 1) The next available line will have an entry indicating the date and time, “Medication Destruction”, the amount destroyed and a zero-ending balance with 2 nurse initials.
 - 2) HH002 will be forwarded to Compliance and Audit Department for inclusion in the EMR.

11. Tidewell colleagues or representative staff may not transport, under any circumstances, medications for disposal on behalf of patient or family member. It is not lawful to do so.

12. Methods of Medication Disposal:

- a. **Household Trash** is one option or method for destruction of medications provided the necessary supplies are available on site to complete the medication disposal. Supplies may include sealable plastic bags, water, inedible substances such as coffee grounds, kitty litter, dirt or detergent.
- b. **Commercial medication deactivation products** are another option or alternative method to dispose of medications. These commercially available products may be provided through hospice or purchased through vendors or pharmacies by patients and families
- c. **Flushing** is an alternative option in selected situations for high-risk medications. A list of medications recommended for disposal by flushing can be found on the FDA website⁴. This list contains many narcotic medications used for treatment of pain. If non-flushing disposal options are not readily available or feasible, it is recommended that patient or family members consider allowing these medicines to be flushed down the sink or toilet as soon as they are no longer needed to avoid accidental harmful or fatal ingestion.
- d. “Hospice Medication Destruction Disposal Techniques” CLIN058 is available for patient or caregiver education to how to physically disposal of medications.
- e. Patient and families can attend **DEA Take Back Events** for medication disposal. Access the DEA’s website for more information about drug disposal, National Prescription Drug Take-Back Day events and to locate a DEA-authorized collector in patient’s area.

- f. Patient and families may elect to dispose of medications at local medication disposal sites. A “Let Me Teach You” Medication Disposal Collection Sites is available for patient or caregiver education.

References:

Medicare Hospice Conditions of Participation. Subpart D: 418.106 Drugs and Biologicals, Medication Supplies and Durable Medical Equipment. Standards: Labeling, Disposing and Storing of Drugs and Biological,

NHPCO Survey Readiness Initiative Medicare CoPs Compliance Guide for Hospice Providers January 2015. Section 418.106 Drugs and Biologicals, Medical Supplies and DME. NHPCO.org/wp-content/uploads/Regulatory_Compliance_Toolkit.pdf

DOJ, DEA, Disposal of Controlled Substances, Final Rule. Vol 79, No. 174 Federal Register 53520 (September 9th, 2014). GovInfo.gov/content/pkg/FR-2014-09-09/pdf/2014-20926.pdf

Medicines Recommended for Disposal by Flushing Listed by Medicine and Active Ingredient: FDA.gov/downloads/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/UCM337803.pdf

US FDA Consumer Health Information. “How To Dispose of Unused Medicines.” FDA.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm

Drug Enforcement Agency National Prescription Drug Take Back Day Dea

HOSPICE MEDICATION DESTRUCTION AND DISPOSAL TECHNIQUES

Individuals should wear gloves during medication destruction to prevent unintended exposure through direct skin contact with liquids, gels and patches containing medication.

Household Trash Destruction Procedure

Medication destruction is accomplished by use of an alternative disposal container such as a sealable plastic bag, addition of water and inedible substances such as coffee grounds, kitty litter, dirt or detergent. Medications may be added sequentially in the following order to the disposal container.

1. Add solid drugs such tablets or capsules crushing them using a can or other heavy object as much as possible to enhance their ability to partially dissolve.
2. Add liquid drugs such as oral liquid drugs, rectal liquid drugs or liquid injectable drug vial contents.
3. Add gel drugs after opening the individual gel packets and squeezing out contents.
4. Add suppositories after removing outer wrapping.
5. Add patches by removing new patches from their packaging or used patches from the patient. Fold patches in half so that the adhesive/sticky side of the patches adheres to itself.
6. Add water to the disposal container to roughly double the volume in order to make slurry.
7. Add coffee grounds, kitty litter, dirt or other inedible substance to the slurry. Mix contents.
8. Close and seal the disposal container.
9. Place the disposal container in another opaque bag such as a grocery or trash bag and tie closed.
10. Throw sealed disposal container in regular trash (not recyclable trash).
11. Empty glass or plastic vials, drug wrappers or other drug packaging may be discarded in the regular or recyclable trash as appropriate.
12. Remove or mark through any personal identification information from prescription labels on containers and discard in regular or recyclable trash if appropriate.

Flush Destruction Procedure

The USFDA maintains a “should flush” drug list. Any drugs appearing on this list are recommended to be destroyed quickly. If non-flushing options are not feasible these medications may be destroyed by flushing. The FDA, Office of National Drug Control and DEA have determined that the risk of fatal exposure or unauthorized use of these “should flush” medications outweigh any potential negative environmental effects from flushing. Medication destruction is accomplished by use of toilet and sewer/ septic system.

1. Medications may be added individually one at a time to the toilet bowl or one at a time to a single container and then by emptying the container contents simultaneously to the toilet bowl while flushing.
2. Add solid drugs such as tablets or capsules.
3. Add liquid drugs such as oral liquid drugs, rectal liquid drugs or liquid injectable drug vial contents.
4. Add patches drugs by removing new patches from their packaging or used patches from the patient. Fold patches in half so that the adhesive/sticky side of the patches adheres to itself.
5. Add gel form drugs after opening the individual gel packets and squeezing out contents.
6. Add suppositories after removing outer wrapping.
7. Flush medications down the toilet.
8. Empty glass or plastic vials; drug wrappers or other drug packaging may be discarded in the regular or recyclable trash as appropriate.
9. Remove or mark through any personal identification information from prescription labels on containers and discard in regular or recyclable trash if appropriate.

HELPFUL INFORMATION

FINAL ARRANGEMENTS

People often do not think about final arrangements until after a person has died. Suddenly, decisions need to be made quickly during a stressful time. It is often helpful to plan ahead by asking your loved one about their final wishes. Whatever the wishes may be, planning for them can relieve stress during an emotional time.

Funeral Services

There are many things to consider when planning a viewing and graveside service: the choice of casket and marker, arrangements with the funeral home, transporting the remains if the burial is out of state, the paperwork involved, the list goes on. The Funeral Rule, enforced by the Federal Trade Commission, requires funeral directors to provide an itemized price list of their services and all products they offer.

Burial

Burial involves decisions regarding viewing, casket, cemetery plot, marker and perpetual care of site. Memorial services can be held without a viewing at your home, place of worship or any other location.

Cremation

Cremation provides cremains that can be buried, placed in an urn at a cemetery facility distributed as your loved one or the family desires.

Body Donation

Body donation allows the remains to be used for scientific research or medical research. Often the survivors can receive the cremains later to honor in whatever manner desired. There are several organizations and universities that will accept body donations. These arrangements must be completed prior to death. Please ask your Tidewell social worker for information and assistance if needed.

Burial at Sea

Active military personnel and veterans can have their bodies or cremains buried at sea by the U.S. Navy through the mortuary program. Private Citizens can arrange for burial at sea through a funeral home or can arrange it themselves, following guidelines that can be found on The Environmental Protection Agency website EPC.gov/Ocean-Dumping/Burial-Sea.

CHOOSING A FUNERAL HOME

The following questions can help when selecting the funeral home and services of your loved one. If possible, it is recommended that you consider more than one facility, visit with the funeral directors and tour the facilities. Meeting the funeral staff and feeling comfortable with them can help you and your family to create a meaningful personalized service. It is also recommended to openly discuss your budget with the funeral director so he or she can assist in selecting service options that will meet your loved ones wishes. Your Tidewell social worker is available to help you identify your needs and prepare for this decision. While Tidewell staff members do not make recommendations for which funeral homes or cremation services to use, they do have a list of services in your area.

- ☐ Does the funeral home physical building meet your standards? Is it clean? Have enough space?
- ☐ Does it employ licensed funeral directors?
- ☐ Is the funeral home established in the community?
- ☐ Have any of the licensees been disciplined by the state regulatory board?
- ☐ Is there a website you can visit for more information?
- ☐ Is the funeral director willing to come to you to make arrangements?
- ☐ Is the funeral home affiliated with a local cemetery that might offer special savings?
- ☐ Are pre-arrangements transferable if you should relocate out of town?
- ☐ Are 100 percent of the ashes recoverable?
- ☐ Are services available regardless of financial ability?
- ☐ Is there a service guarantee?
- ☐ Are personalized services provided, such as DNA (lock of hair), video tributes, online memorials? What are they?
- ☐ Are aftercare services included and what are they?
- ☐ Does the funeral home own and operate a crematory? If not, who does the funeral home use and where is it located?

- ☐ Can you meet the crematory personnel and/or witness different aspects of cremation?
- ☐ Does the funeral director assist the family with arranging religious services and cemetery arrangements?
- ☐ Is there a mausoleum?
- ☐ Are there property selections for cremation?
- ☐ Do they have a veterans' section?
- ☐ Additional questions?

THE MEMORIAL/FUNERAL SERVICE: A CELEBRATION OF LIFE

A memorial service provides a sense of closure for the survivors. Despite the grief and fatigue, spending time with friends and family is a step in the healing process. Sacred texts, poetry and music are commonly used in planning a memorial service. Reflect on your loved one's life. Think about their values, special events, life's work, hobbies, travels and contributions. Honoring your loved one will help you understand and cope with your grief.

In most cases, planning a memorial service falls to the immediate survivors. It is also common for your loved one to participate in this planning, if they are able. If the patient has reached an understanding and acceptance about the terminal illness, planning a memorial service jointly can be very supportive for everyone.

Things to Consider

Music: More than anything else, music may affect your feelings and the atmosphere in which you remember your loved one. Select hymns, songs or other music that are your loved one's favorites and bring comfort or celebrate their life.

Readings: Reflective passages of sacred text, poems and short stories are all helpful in remembering your loved one. Some faith traditions may require that scripture be read, but many faiths are flexible and will include other types of readings as well.

Symbols of life: Share pictures, items from your loved one’s hobbies, avocations, important moments in life and symbols of accomplishments or milestones achieved.

Homily, eulogy, meditation: Integrate the music, readings and symbols with your loved one’s life and indicate ways they inspired others.

Tidewell Hospice chaplains are available to assist you in planning a memorial service for your loved one, and may be available to conduct the funeral or memorial service.

PLANNING THE SERVICE

Speak with the Tidewell social worker or chaplain if you need assistance with planning the funeral or memorial service. They are generally able to answer most of your questions.

If you have made funeral arrangements or wish to use the services of a specific funeral director, record that information here:

Funeral home: _____

Funeral director: _____

Address: _____

Telephone: _____

Cemetery: _____

Plot: _____

Specific instructions: _____

If a family member is flying into town to visit a loved one and/or plans to attend the funeral service, they can notify the airline of the reason for the flight when making reservations. Some airlines will issue the ticket at a reduced rate.

Memorial Form

Supporting families through the many stages of dealing with on advanced illness is a vital part of Tidewell's mission. One of the ways we are able to do this is to offer assistance in planning for the time ahead.

It is important to have accurate memorial information available for newspapers and the funeral director, and most of it can be gathered in advance. Tidewell staff members are willing to help you in any way possible.

Patient Information

Name: _____

Address: _____

City/State: _____

Birthplace: _____

Came to area from/when: _____

Church/religious affiliation: _____

Career/type of employment: _____

Number of years: _____

Family members: _____

Organizations/offices: _____

Major achievements/honors: _____

Military service/recognition: _____

Memorial donations*: _____

Other Information: _____

SUPPORTING TIDEWELL'S MISSION

Often, during the course of care, a family member will ask if there is some way to help Tidewell fulfill its mission of providing care, comfort and support.

For three essential reasons, the answer is a resounding yes.

First, unlike hospitals, Tidewell receives no federal or state funds to cover costs for treating indigent patients and is, therefore, dependent on philanthropic support. Each year Tidewell provides nearly \$5 million in unreimbursed care assuring that everyone receives the full complement of services. This includes hospice and palliative care for those without financial means or who are uninsured or under-insured. This care is free and supported by gifts to the Tidewell Foundation.

Secondly, Tidewell is fully committed to providing a comprehensive array of services that respond to individual needs – many of which are not covered through insurance. Therapies such as massage, music or pet are prescribed as alternatives to pain or anxiety medications. Grief and bereavement counseling for caregivers and family members is available well beyond the death of the loved one.

Finally, Tidewell continually evolves to meet the needs of patients and families through innovative programs and services – all funded exclusively through philanthropic support. For example, one new program brings comfort to patients with dementia and another offers relief for those who are bed-ridden and suffering wounds. Tidewell created a nurse residency program in response to the national nursing shortage. Blue Butterfly provides evidence-based grief services for children 5-18 and their families. This service is available for anyone in our four county service area free of charge.

All contributions to Tidewell are used within its four-county service area (Sarasota, Manatee, Charlotte, DeSoto).

There are many ways to support Tidewell in delivering exceptional care while honoring the memory of your loved one. You may consider:

- Memorials: Donations to the Tidewell Foundation sent in memory of a friend or loved one.
- Obituaries/funeral services: Request donations to the Tidewell Foundation instead of sending flowers.
- Annual support: Contributions to the Tidewell Foundation can be used where the need is the greatest or direct your gift to a particular program or location.
- Remembrance Walkways: Naming opportunity to pay special tribute to loved ones while supporting Tidewell.
- Third-party special events: Host an event to benefit Tidewell.
- Bequests: Planned giving to the Tidewell Foundation in the form of wills, trusts, annuities and paid-up life insurance policies form a significant portion of donor support.
- Tidewell Angel: Honor your Tidewell caregiver or volunteer, who receives acknowledgement of your gift and a special Tidewell Angel pin.
- Vehicle donation: Donate a vehicle you no longer use-car, truck, trailer, boat, RV or motorcycle. Tidewell will arrange for the vehicle to be picked up and towed at no cost to you
- Stock: Donors can receive the same income tax deduction for a gift of stock as for a gift of cash, plus possibly avoid capital gains taxes.
- Tangible property: The Tidewell Foundation gratefully accepts a variety of tangible gifts, including real estate property and other items of value.
- Tidewell Treasures: Treasures gratefully accepts all donations of gently used clothing, furniture and household items. If you wish to donate items weighing more than 25 pounds, please contact Treasures at (941) 882-4467 to arrange for pick up. TidewellTreasures.org.

Thank you for the privilege of caring for your loved one.

Your Tidewell Team

The Tidewell Foundation is tax exempt under the U.S. Internal Revenue Service code and all contributions are tax deductible to the fullest extent allowed by law. A copy of official registration and financial information may be obtained from the Florida Division of Consumer Services, registration number CH63240.

To view Tidewell Foundation's annual reports visit TidewellFoundation.org/About-Us/Corporate-Documents. Checks can be made payable to the Tidewell Foundation and forwarded to :

Tidewell Foundation
3550 South Tamiami Trail, Sarasota, FL 34239

Individuals who wish to make a credit card donation can visit our website at TidewellFoundation.org.

To learn more about to the Tidewell Foundation and naming opportunities, call (941) 552-7546 or visit TidewellFoundation.org.



NOTICE OF PRIVACY PRACTICES

EMPATH-STRATUM, INC., DBA EMPATH HEALTH

Empath Health offers a variety of programs in its continuum of care. This Notice of Privacy Practices applies to all of its programs affiliated with Empath-Stratum, Inc. This joint Notice of Privacy Practices describes how Empath-Stratum, Inc. (DBA Empath Health) may use your health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations.

USE AND DISCLOSURE OF HEALTH INFORMATION

Empath Health may use your health information, including photographs, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. Empath Health has established policies to reasonably protect health information as defined in the Health Insurance Portability and Accountability Act (HIPAA) Privacy and Security Rules. Empath Health has established policies to guard against unnecessary disclosure of your health information. Empath Health will limit its own uses and disclosures of your health information to the minimum amount necessary to accomplish this purpose.

To Provide Treatment. Empath Health may use your health information to coordinate treatment with others involved in your care, such as your physician, members of the care team and other health care professionals who assist in providing care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. Empath Health also may disclose your health care information to individuals outside the organization who are involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

To Obtain Payment. Empath Health may use and disclose your health information to obtain payment for services they provide to you, unless you request that they restrict such disclosures to your health plan when you have paid out-of-pocket and in full for services rendered.

To Conduct Healthcare Operations. Empath Health may use and disclose health information for its own operations in order to facilitate its function and as necessary to provide quality care to all. For example, Empath Health may use or disclose your health information to perform quality assessment activities or evaluate the performance of its staff.

Your Authorization. In addition to its use of your health information for treatment, payment or health care operations, you may give Empath Health written authorization to use your health information or to disclose it to anyone for any purpose. If you give such an authorization, you may revoke it in writing at any time. Your revocation will not affect any use or disclosures permitted by your authorization while it is in effect. Unless you give Empath Health a written authorization, they cannot use or disclose your health information for any reason except those described in this notice.

If you are in an inpatient or residential facility, Empath Health may disclose certain information about you in a directory, including your name, your general health status, your religious affiliation and your location while you are in the facility. Empath Health may disclose this information to people who ask for you by name. Please inform Empath Health if you do not want your information to be included in the directory.

Persons Involved in Care. Empath Health may use or disclose health information to notify, or assist in the notification of (including identifying or locating) a family member, your personal representative or another person responsible for your care, of your location, your general condition or your death. If you are present, then prior to use or disclosure of your health information, Empath Health will provide you with an opportunity to object to such uses or disclosures. In event of your incapacity or emergency circumstances, Empath Health will disclose health information based on a determination using its professional judgement disclosing only health information that is directly relevant to the person's involvement in your health care.

For Fundraising Activities. Empath Health may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for Empath Health. Empath Health may also release this information to related Empath Health foundations.

If you do not want Empath Health to contact you or your family, notify the Empath Health Privacy Officer, 5771 Roosevelt Blvd., Clearwater Florida. (727) 586-4432.

For Appointment Reminders. Empath Health may use and disclose your health information to contact you as a reminder that you have an appointment for a visit.

For Treatment Alternatives. Empath Health may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

Disclosures to our Business Associates. Empath Health may share your health information with third party "business associates" that perform various activities (e.g., billing, transcription services) for Empath Health. Whenever an arrangement between Empath Health and a business associate involves the use or disclosure of your health information, Empath Health will have a written contract that contains terms that will protect the privacy of your health information.

When Legally Required. Empath Health will disclose your health information when it is required to do so by any Federal, State or local law.

When There Are Risks to Public Health. Empath Health may disclose your health information for public activities and purposes like reporting vital events such as birth or death, tracking medical devices or reporting communicable diseases.

To Report Abuse, Neglect or Domestic Violence. Empath Health is allowed to notify government authorities if it believes a patient is the victim of abuse, neglect or domestic violence. Empath Health will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

To Conduct Health Oversight Activities. Empath Health may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. Empath Health, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

In Connection with Judicial and Administrative Proceedings. Empath Health may disclose your health information in the course of any judicial or administrative proceeding, in response to court or administrative order or in response to a subpoena, discovery request or other lawful process, but only when Empath Health makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

For Law Enforcement Purposes. As permitted or required by State Law, Empath Health may disclose your health information to a law enforcement official for certain law enforcement purposes such as:

- Required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena 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 or are suspected to be the victim of a crime.
- To a law enforcement official if Empath Health has a suspicion that your death was the result of criminal conduct, including criminal conduct at Empath Health.
- In an emergency in order to report a crime.

To Coroners and Medical Examiners. Empath Health may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

To Funeral Directors. Empath Health 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. Empath Health may disclose your health information to funeral directors prior to and in reasonable anticipation of your death, if deemed necessary to fulfill their duties.

For Organ, Eye or Tissue Donation. In the event you have chosen to be a donor, Empath Health may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

For Research Purposes. Empath Health may, under very select circumstances, use your health information for research. Before Empath Health discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.

In The Event of a Serious Threat to Health or Safety. Empath Health may, consistent with applicable law and ethical standards of conduct, disclose your health information if Empath Health, 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 Specified Government Functions. In certain circumstances, the Federal regulations authorize Empath Health to use or disclose your health information to facilitate specified 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 Workers' Compensation. Empath Health may release your health information for workers' compensation or similar programs.

Authorization to Use or Disclose Health Information

Other than as stated above, Empath Health will not disclose your health information other than with your written authorization. You may revoke that authorization in writing at any time. However, Empath Health is unable to retrieve any disclosures that were already made with your permission and that Empath Health is required to retain for its records of care.

Authorization to Use or Disclose Health Information

Your written authorization is required for most uses and disclosures of psychotherapy notes; uses and disclosures of health information for marketing purposes; and disclosures that are a sale of health information. You may revoke your authorization in writing at any time except to the extent that Empath Health have taken action in reliance upon the authorization.

Unless during your life you (or your lawful representative) expressly state in writing that a specific person or entity is authorized; after your death, to request your health information; a court order may be required pursuant to Florida Statute Section 400.611(3) before Empath Health will release your records.

Your Rights with Respect to Your Health Information

You have the following rights regarding your health information that Empath Health maintains. If you wish to exercise this right, you may contact the Privacy Officer.

Right to Request Restrictions. You have the right to request that Empath Health place additional restrictions on our use or disclosure of your health information. Empath Health is not required to agree to these additional restrictions, but if they do, they will abide by the agreement (except in emergency). In the event you pay out-of-pocket and in full for services rendered, you may request that Empath Health not share your health information with your health plan. Empath Health must agree to this request.

Right to Receive Confidential Communications. You have the right to request that Empath Health communicate with you in alternative means. For example, you may ask that Empath Health only conduct communications pertaining to your health information with you privately with no other family members present. Empath Health 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 you request a copy of your health information, Empath Health may charge a reasonable fee for copying and assembling costs associated with your request.

Right to an Electronic Copy of Electronic Medical Records

If your protected health information is maintained in an electronic format, you have the right to request that an electronic copy of your record be given to you or transmitted to another individual or entity. Empath Health will make every effort to provide access to your protected health information in the form or producible in the form or format, you request. Your record will be provided in either standard electronic format or if you do not want this form or format, a readable hard copy form. Empath Health may charge you a reasonable, cost-based fee for the labor associated with transmitting the electronic medical record.

Right to Amend Health Care Information. You or your representative has the right to request that Empath Health amend your records, if you believe that your health information is incorrect or incomplete. That request must be in writing and explain why the amendment is necessary. Empath Health may deny your request under certain circumstances.

Right to an Accounting of Disclosures. You or your representative have the right to request an accounting of disclosures of your health information made by Empath Health for reasons, other than treatment, payment or operations. The request must specify the time period for the accounting which may not be older than six (6) years. Empath Health will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a cost-based fee.

Right to a Paper Copy of This Notice. You or your representatives have a right to a separate copy of this Notice at any time, even if you or your representative have received this Notice previously. You may also obtain a copy of the current version of Empath Health's Notice of Privacy Practices at its website EmpathHealth.org.

Right to Receive Notice of Breach of Protected Health Information. In the event of any unauthorized acquisition, access, use or disclosure of Protected Health Information; Empath Health, will fully comply with the breach notification requirements, including any and all regulations which have been or may be promulgated, which will include notification to you of any impact that breach may have had on you.

Right to Additional Florida Privacy Protections. You have the right to any additional privacy protection granted through Florida law.

Duties of Empath Health

Empath Health is required by law to maintain the privacy of your health information and to provide this Notice of its duties and privacy practices to you or your representative. Empath Health is required to abide by the terms of this Notice as may be amended from time to time. Empath Health 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 Empath Health makes material changes to its Notice; Empath Health will make a copy of the revised Notice available to you or your appointed representative.

You have the right to express complaints to Empath Health and to the Secretary of US Department of Health and Human Services, Office of Civil Rights, if you believe that your privacy rights have been violated. Complaints to Empath Health should be made in writing to HIPAA Privacy Officer, 5771 Roosevelt Blvd., Clearwater, Florida 33760. Empath Health encourages you to express any concerns you may have regarding the privacy of your information and offers its assurance that you will not be retaliated against in any way for filing a complaint.

Complaints to the Department of Health and Human Services can be made online at [HHS.gov/OCR/Privacy/Hipaa/Complaints](https://www.hhs.gov/ocr/privacy/hipaa/complaints) or U.S. Department of Health and Human Services, Sam Nunn Atlanta Federal Center, Suite 16T70, 61 Forsyth Street, S.W., Atlanta, GA 30303-8909; Voice Phone (800) 368-1019; fax (404) 562-7881.

Contact Person

Empath Health has designated the HIPAA Privacy Officer as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. To make a request or ask a question, you may contact the HIPAA Privacy Officer at 5771 Roosevelt Blvd., Clearwater, FL 33760 or at (727) 586-4432.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al (727) 467-7423.

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele (727) 467-7423.

Effective Date

This Notice was originally effective April 14, 2003 and updated on:

September 18, 2013

February 4, 2015

July 26, 2017

October 19, 2018

August 25, 2022

ADM007 Rev 10/4/22

NONDISCRIMINATION IN HEALTH PROGRAMS AND ACTIVITIES

Discrimination is Against the Law

Tidewell Hospice complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Tidewell Hospice does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Tidewell Hospice:

- Provides free aids and services to people with disabilities to communicate effectively with us, such as:
 - o Qualified sign language interpreters
 - o Written information in other formats (large print, audio, accessible electronic formats, other formats)
- Provides free language services to people whose primary language is not English, such as:
 - o Qualified interpreters
 - o Information written in other languages

If you need these services, contact Tidewell Hospice.

If you believe that Tidewell Hospice has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Civil Rights Coordinator

Tidewell Hospice
5595 Rand Boulevard
Sarasota, FL 34238
(941) 552-7500

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Tidewell Hospice is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services

200 Independence Avenue SW, Room 509F, HHH Building, Washington, D.C. 20201
800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at www.hhs.gov/ocr/office/file/index.html.

Tidewell Hospice complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

ATTENTION: If you speak Spanish, French Creole, Vietnamese, Portuguese, Chinese, French, Tagalog, Russian, Arabic, Italian, German, Korean, Polish, Gujarati or Thai, language assistance services, free of charge, are available to you. Call (855) 843-3935.

Spanish

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al (855) 843-3935.

French Creole

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele (855) 843-3935.

Vietnamese

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số (855) 843-3935.

Portuguese

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para (855) 843-3935.

Chinese

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 (855) 843-3935.

French

ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le (855) 843-3935.

Tagalog

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa (855) 843-3935.

Russian

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните (855) 843-3935.

Arabic

مقرب لصتا. ناجملاب لكل رفاوتت ةيوعللل ةدعاسملا تامدخ نإف، ةغلللا ركذا شحتت تنك اذا: ةظوحلم
855-TIDEWELL (855-843-3935).

Italian

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero (855) 843-3935.

German

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: (855) 843-3935.

Korean

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다.
(855) 843-3935 번으로 전화해 주십시오.

Polish

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer (855) 843-3935.

Gujarati

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિઃશુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો (855) 843-3935.

Thai

เรียน: ถ้าคุณพูดภาษาไทยคุณสามารถใช้บริการช่วยเหลือทางภาษาได้ฟรี โทร (855) 843-3935.



Tidewell is CHAP Accredited

Tidewell Hospice has been granted accreditation by the Community Health Accreditation Partner (CHAP), signifying that Tidewell demonstrates the highest level of excellence in its service to patients and families who are living with advanced illness. CHAP accreditation is a voluntary process. Together with the mandatory licensure by the Agency for Health Care Administration (AHCA), CHAP accreditation provides assurance that Tidewell meets and exceeds the gold standard for a high level of care and maintains an ongoing commitment to continued improvement and quality.



Toll free (855) 843-3935 | TidewellHospice.org

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