Treasure Coast Hospice
A TREASURE HEALTH SERVICE

PATIENT & CAREGIVER TRAINING GUIDE

A compassionate and comprehensive guide for our patients and their caregivers.

Treasure Coast Hospice has earned the Gold Seal of Approval® for hospice accreditation from The Joint Commission.

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A LETTER FROM OUR **PRESIDENT & CHIEF EXECUTIVE OFFICER**

Treasure Coast Hospice's team of physicians, nurses, social workers, chaplains, hospice aides, counselors and volunteers are dedicated to caring for your physical and emotional needs. We know how difficult this decision may have been for you and your team wants you to feel comfortable and confident in caring for your loved one. This training guide contains information about the most common questions and problems that may arise during your time with us. You can also access training videos with the QR code below. Your Treasure Coast Hospice team is always available to train you on how to care for your loved one.

A Treasure Coast Hospice nurse is available to help you and your loved one 24 hours a day, 7 days a week by calling 772-403-4500.

Jackie Kendrick, CHPCA
President & Chief Executive Officer

Please use this QR code or the link below to access our caregiver training videos.
TreasureHealth.org/Caregivers

Patient & Caregiver Training Guide

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PAIN

Pain is a complex symptom, there are several types of pain and many causes of it. Pain is extremely personal and unique to the person in pain.

The good news is that there is much a patient, caregiver, and the hospice team can do for managing pain. The hospice team will try to find the reason for the pain and discuss treatment options with you. Medications are usually necessary to relieve pain. The nurse will give you information about medicines, when they are to be administered and what you need to know.

Signs and Symptoms

- Facial grimacing or a frown
- Writhing or constant shifting in bed
- Moaning, groaning, or whimpering
- Appearing uneasy or tense
- Drawing up legs or kicking
- Guarding the area of pain
- Withdrawing from touch to the area of pain
- Pacing
- Changes in mood or behavior

What you can do?

- Relaxing activities such as listening to music, light massage, soaking in a tub of warm water, or guided imagery (picturing enjoyable and relaxing scenes to take one's mind off the pain)
- Distracting activities such as watching TV, playing a game, or just thinking of other things

- Heat or cold (such as a heating pad, warm compress, or ice pack)
- Pleasant smells of certain plants or fragrances (aromatherapy) such as lavender, etc.
- Storytelling, drawing
- Take or administer medications as ordered
- Many side effects can be treated and/or may even stop after taking the medications for a few days.

What to report to the Treasure Coast Hospice Team?

- How severe or intense the pain is (this can be reported as a number using 0 as no pain and 10 as the worst possible pain imaginable)
- Where the pain is located
- If the pain keeps the patient from doing usual activities
- What makes the pain worse
- What makes the pain better
- What does the pain feel like (burning, sharp, stabbing)
- If the pain is constant or come and goes
- How well the pain medication is working
- How much and how often medications are taken (helpful to keep a log)
- Any side effects of the medication
- Concerns about the medication, how to take them or how to administer them
- Irritability from lack of sleep because of the pain
- Need for additional medications

We're Here When You **Need Us**

As a community not-for-profit 501(c)(3) organization, we have proudly served the residents of Martin, St. Lucie and Okeechobee counties since 1982, becoming nationally recognized for the quality of our care and our range of services.

COMMON SIDE EFFECTS OF PAIN MEDICATIONS

Constipation

The passage of hard, dry stools less often than the person's usual bowel pattern. Opioids (such as morphine) are medications that are used for the relief of pain and trouble breathing. Opioids also slow the movement of the bowel which leads to constipation. Constipation during opioid therapy is very common. A plan to prevent this should be started as soon as these medications are prescribed. Laxatives should be taken as regularly as the opioid. For example, if the person takes opioids daily, he/she should also take laxatives daily. **Tell the Treasure Coast Hospice Team if the patient has not had a bowel movement for three (3) days.** A person taking opioids should have a Bowel movement at least every 2-3 days. The stools should not be hard or cause strain.

Sleepiness/Drowsiness

Feeling drowsy or sleepy when starting or increasing a pain medication dose is normal. This is usually temporary, lasting only 48-72 hours. If it lasts longer than this, the dosage of your pain medication can be reduced as needed. Remember, initially it is your body's normal response to a new medication (and also probably a reflection of being able to rest and sleep pain free at last!) **Patient caregivers: if you feel the patient is in their final weeks or days, tell the Treasure Coast Hospice team as soon as possible.**

As a Level Five We Honor Veterans Partner with the VA and other veterans organizations, Treasure Coast Hospice is honored to care for veterans with advanced illness.

Dizziness

When starting, or increasing, a pain medication dose, the patient may experience dizziness for the first couple of days. Dizziness typically decreases within that time. Be careful when changing positions (sitting or standing). The patient may need assistance to prevent falls. **Tell your Treasure Coast Hospice Team about dizziness that does not go away after the first couple of days or if you or the patient has a fall.**

Nausea

Opioids can cause an upset stomach for the first few days, as the body adjusts to the medication. Encourage the patient to eat a light snack (such as crackers) when taking opioid pain medications. Your Treasure Coast Hospice team may also treat nausea with medication until it goes away. **Tell your Treasure Coast Hospice Team about nausea that does not go away, as it may be related to your condition.**

MYTHS ABOUT PAIN MEDICATIONS

Opioids (oh-pee-oyd), often called narcotics, are commonly used in hospice to keep patients comfortable. Many patients, family members, and even healthcare providers are afraid to give these medications because of what they have heard in the news, on television, and from friends. The following information is designed to help dispel some of the myths surrounding the use of opioids.

MYTHS OF OPIOID USE

1. MYTH - "Opioids are addicting"

TRUTH - This fearfulness to take pain medication can lead to suffering. Addiction is a chronic disease in which people have a poor control over drug use and continue to

use the drug despite risk of physical and social harm. Addiction is rare in patients who are terminally ill when the goal of care is comfort. Opioids are strictly monitored and assessed on a routine basis. Always tell your care team if there is a history of drug or alcohol abuse.

2. MYTH - "If a person takes large doses of opioids early in their disease process, the opioids will not be as effective later on when he/she needs higher doses"

TRUTH - Tolerance is a reduced response to a drug used repeatedly. Hospice patients develop tolerance as their disease and symptoms management needs increase. The right dose should give the same relief for quite a while. In many cases, the dose may increase when symptoms are worsening, then treatment could change to a lower dose once relief is reached. If you are worried about this, talk to your care team about preferred options.

3. MYTH - "Giving opioids to a terminally ill patient will speed up death"

TRUTH - Research shows that the use of opioids does not lead to a faster death. It is the disease that causes death, not the pain medicine. The small opioid dose for a hospice patient in their final weeks, days, hours is to be used for comfort and relief of suffering and to allow the patient to experience a peaceful and dignified death. Withholding or withdrawing pain medication at end of life is not appropriate or safe.

4. MYTH - "Opioids cause a person to feel foggy and lose control"

TRUTH - When opioids are taken on a regular basis, tolerance quickly develops and the feeling of being foggy or out of control should go away within a week.

5. MYTH - "Opioids cause respiratory depression"

TRUTH - When opioids are adjusted slowly to provide pain relief, respiratory depression is rare.

DYSPNEA

Dyspnea (disp-nee-uh) is a medical term for an uncomfortable feeling or having difficulty breathing (troubled breathing). This symptom is closely related to heart and lung diseases.

Experiencing difficulty breathing causes anxiety, agitation, fatigue and restlessness. It may also interfere with daily activities such as eating, bathing, walking, talking and visiting with friends and family. The good news is there is much a patient, caregiver and the hospice team can do for shortness of breath. The hospice team will try to find out the cause and discuss treatment options with you.

Signs and Symptoms

- Can be described as not getting enough air (a feeling that you cannot catch your breath, like the room is closing in or that there is not enough air in the room)
- Rapid breathing
- Tightness in chest
- A feeling of being “winded”
- Inability to speak in full sentences
- Fear or panic about not getting enough air in or out of the lungs

What you can do?

- Remain calm and reassuring for the patient
    - Keep environment quiet to decrease feeling of anxiety
- Reposition the patient until his/her breathing improves
    - Position patient upright in bed (elevating the head of bed)
    - Place pillows under the patient’s head, back and neck
    - Sit patient up on the side of the bed leaning over a bedside table
    - Transfer the patient to a chair or recliner

- Increase air movement in the room by opening a window or using a fan
- Apply a cool cloth to the patient's head or neck
- Lead the patient in the "pursed lip breathing" technique (take slow, deep breaths, breathing in through nose and then breath out slowly and gently through pursed lips/lips that are "puckered" as if you were going to whistle.
- Relaxing activities such as prayer, medication, calming music, and massage
- Administer oxygen if ordered
- Administer medications as ordered for shortness of breath

What to report to the Treasure Coast Hospice Team?

- Breathing problems that continue or worsen
- New or worsening cough
- Need for additional oxygen or medication supplies for the patient

CONSTIPATION

Hospice patients may experience constipation as a result of taking pain medication, moving less, eating and/or drinking less, or transitioning into a new phase of illness.

They may suffer hard, difficult to pass or infrequent stools that cause a great deal of anxiety, pain, and agitation. The good news is there are things the patient, caregiver and hospice team can do for constipation. While bowel habits can vary from person to person, hospice patients should have a bowel movement at least once every three (3) days.

Signs and Symptoms

- Dry, hard (pellet-like) stools

- Inability to pass stool
- Abdominal bloating
- Nausea
- Loss of appetite
- Oozing, watery leakage of stool
- Rectal pain or pressure

What you can do?

- If the patient is physically able to tolerate, or if his or her diet allows:
  - Eat fibrous foods
  - Walk or do light Range of Motion (ROM) exercises
  - Sit upright on toilet, bedside commode, or bedpan
  - Avoid fiber supplements (like Metamucil) as these can make symptoms worse
- Keep a record of the patient's bowel movements including date/time, consistency of stool (hard, soft, or watery)
- Take or administer laxatives/stool softeners as ordered
- Talk to your Treasure Coast hospice nurse about prescribing a stool softener or laxative to help manage constipation.

What to report to the Treasure Coast Hospice Team?

- The patient feels constipated or has not had a bowel movement in three (3) days
- Other symptoms such as pain, cramping, tenderness, feeling of fullness or bloating, nausea/vomiting, straining, diarrhea, pain, or rectal bleeding

Our highly qualified team of physicians, nurses, nursing assistants, social workers and chaplains is a resource to individuals and families. We educate people about their options long before, during and after health issues arise, offering tools and guidance that allow you to individualize your healthcare at every stage.

ANXIETY

Anxiety is a feeling or deep sense that things are not right. Experiencing anxiety at times is normal and can help people focus on completing tasks or to deal with stressful situations.

However, when these feeling become strong, extreme and interfere with daily living, help should be requested to manage anxiety. In hospice patients, loss of control can sometimes create stress and feelings of nervousness. Anxiety can also be caused by uncontrolled symptoms such as pain or shortness of breath, uncertainty about what comes next, concerns about conflicts with family or friends and concerns about loss, legacy or financial issues.

Signs and Symptoms

- Fear
- Worry
- Sleeplessness, disturbing dreams or nightmares
- Confusion
- Rapid breathing
- Racing heartbeat
- Tension
- Shaking
- Inability to relax or get comfortable
- Sweating
- Problems paying attention or concentrating

What can you do?

- Activities that have helped patients anxiety in the past

- Allowing patient to express thoughts and feelings
- Playing soothing music
- Keep surrounding calm
- Massaging arms, back, hands and feet
- Avoid caffeine and alcoholic beverages
- Provide reassurance and support
- Treating physical problems, such as pain, that can cause anxiety
- Taking or administering medications as prescribed
- Ask the patient what they need? Or how can I assist you?

What to report to the Treasure Coast Hospice Team?

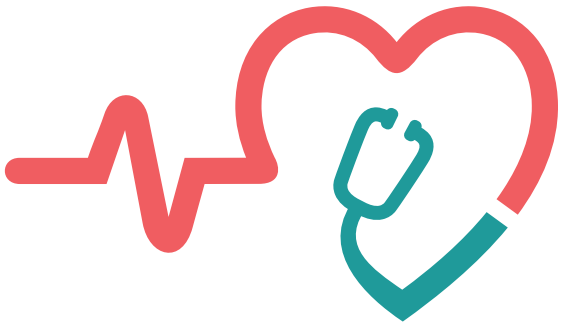
- Past history of anxiety and/or depression
- Feelings that may be causing anxiety (like a fear of dying or worrying about money)
- Concerns about illness
- Signs and symptoms that anxiety is changing, getting worse or not responding to your current interventions

RESTLESSNESS

Restlessness is an inability to rest, relax or concentrate. Extreme restlessness is sometimes called agitation. Restlessness is commonly seen in patients in the last 48 hours of life.

It is important to report signs of restlessness to the hospice team so the hospice team can assist you in identifying what may be causing this symptom and ways to help the patient seek relief from any tension or fear that they may be experiencing.

Signs and Symptoms



- Muscle twitching
- Moving around without a known reason
- Pulling at the sheets, covers or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

What you can do?

- Speak quietly and calmly
- Reduce the amount of noise in the room to decrease stimulation
- Offer relaxation activities like playing soothing music
- Keep things calm, for example: decrease number of visitors
- Read favorite stories, poems, etc. in a calm voice
- Hold the person's hand, give them a gentle massage
- Keep the person safe, for example: do not leave the person alone while restless and check frequently when calm
- Administer prescribed medications as ordered for restlessness

What to report to the Treasure Coast Hospice Team?

- Any signs of restlessness
- Inability to administer medications
- Things that make the restlessness worse
- Things that make the restlessness better
- Concerns that you may have as a caregiver to cope
- Need for support
- Situations that might be unsafe

Patients receive hospice care in their own homes, in hospitals, in nursing homes or assisted living residences, or in one of our three Inpatient Units.

SWELLING (EDEMA)

Edema is unusual fluid buildup in the feet, ankles, legs, arms, hands or face. Congestive Heart Failure (CHF), liver, kidney or thyroid disease, and cancer can cause edema.

Medications and diets with high salt can make the swelling worse.

Signs and Symptoms

- Swollen joints, extremities or face
- Trouble breathing
- Tightness in the skin or clothing
- Indents or dimples left by accessories such as rings, watches or necklaces
- Fluid oozing from the skin

What you can do?

- Elevate the patient's head, arms and/or legs to a comfortable position
- Avoid sitting, standing or crossing legs for long periods of time
- Limit consumption of high amounts of sodium (salt)
    - Examples are canned soups, processed foods and preserved meats
- Wear compression stockings
    - Your Treasure Coast Hospice team can discuss this option with you and train you on their use
- Medications (such as diuretics) may be needed to treat edema
    - Your Treasure Coast Hospice nurse can discuss this option with you and train you on potential side effects and dosage frequency

What to report to the Treasure Coast Hospice Team?

- Any new or changed swollen areas
- Tenderness or pain in a reddened area
- Changes in the color or temperature of the skin
- Trouble breathing or a persistent cough

NAUSEA & VOMITING

There are many different causes of nausea and vomiting that may be related to the hospice patient's illness or treatment.

Some common causes include strong odors, tastes or sights, heartburn, constipation or bowel blockage, reaction to some medications, anxiety, urinary tract infection and brain tumors. It is important to report nausea and vomiting to your Treasure Coast Hospice team so we can try to discover the underlying reason in order to offer treatment options for you. Identifying and treating the cause can increase comfort and improve quality of life.

Signs and Symptoms

- Nausea: An unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting
- Vomiting: The emptying of stomach contents

What can you do?

- Comfort measures:
  - Cool washcloth to the forehead, neck and wrists
  - Increase air flow by opening a window or placing a small fan in the room
  - Loosen the patient's clothing
  - Engage in relaxing activities that may distract from the nausea, such as listening to music, watching TV, working puzzles, sketching or drawing, or reading

- Food and Fluid offerings:
  - Offer small meals with small amounts of fluid to drink
  - Encourage sipping carbonated drinks that have gone flat
  - Provide sips of water or ice chips before patient eats again
  - Provide frequent mouth care

- Avoid the following:
  - Odors that can cause nausea such as fried foods, strong perfumes and deodorizers
  - Feeding/eating immediately after vomiting
  - Juices (such as cranberry, grape, apple)
  - Fried foods, milk products, or foods with strong smells

- Use medications as ordered by the Hospice Team

What to report to the Treasure Coast Hospice Team?

- Amount and frequency of nausea and vomiting
- Description of vomited fluid
- Change in mental status
- What makes it better/what makes it worse
- If actions taken to relief nausea and vomiting are not providing relief

Treasure Coast Hospice Foundation

Through the generous support of our community, the Treasure Coast Hospice Foundation supports the mission of Treasure Coast Hospice by funding a variety of programs from our Grief Support services and Inpatient Units to our Complementary Therapies program.

FATIGUE

Fatigue is defined as feeling tired, exhausted or generally lacking energy. This is a common symptom in both hospice patients and their primary caregivers.

In hospice patients, fatigue may be caused by the person's illness, treatment, medications, emotions and other changes. For the caregiver, it can be compassion fatigue and burnout. Education and support are essential with managing fatigue.

Signs and Symptoms

- Increased agitation or restlessness
- Decreased motivation or lack of interest
- Emotional numbness
- Anxiety or sadness
- Sleep disruptions

What can you do?

- Tell your Treasure Coast Hospice team about signs and symptoms you or the patient are experiencing
- Listen to your body and rest when you are feeling tired
- Establish a routine bedtime
  - Take shorter naps earlier in the day
  - Avoid caffeine before bedtime
  - For patients: Wear oxygen to sleep, if prescribed
- Prioritize and plan activities you enjoy
  - Allow time for self-care
  - Utilize respite care

- Eat nutritious foods in small, easy-to-digest portions, as able
  - Protein, beans, fruits and vegetables
  - Ensure or Boost

What to report to the Treasure Coast Hospice Team?

- Lifestyle or behavioral changes
- Treatments that are not working
- Medication side effects

SADNESS & DEPRESSION

Sadness is normal and expected; however, depression can be challenging. Depression is a strong feeling of sadness that lasts more than two weeks.

If left untreated, it can lead to physical, or mental symptoms and decreased quality of life. A person living with a serious illness can feel wide ranges of emotions; such as sadness, grief, anxiety, anger, and fatigue. The important people for them can also feel these emotions. Discussion with your Treasure Coast Hospice team can help to determine the cause of your symptoms and to find an appropriate plan of care.

Signs and Symptoms

- Loss of interest in enjoyable activities
- Changes in mood and behavior
- Changes in appetite
- Withdrawal from family and friends
- Change in sleeping schedule (insomnia or exhaustion)

- Thoughts of death or suicide
- Feelings of worthlessness, hopelessness, or guilt
- No interest or pleasure in daily activities
- Difficulty focusing or thinking

What you can do?

- Try calming relaxation techniques:
  - Listen to soothing music
  - Deep breathing exercises
- Optimize physical status with rest and nutrition
- Express thoughts and feelings with the Treasure Coast Hospice Social Worker and/or Spiritual Care Coordinator
- Ask about Treasure Coasts Hospice Complementary Therapies (aromatherapy, music therapy, massage)
- In combination with holistic treatments, a Treasure Coast Hospice nurse, or medical provider, is always available to discuss with you medication options, potential side effects, and frequency of when to give prescribed medications.

What to report to the Treasure Coast Hospice Team?

- Past history of anxiety and/or depression
- Other symptoms such as pain, nausea, or trouble breathing
- Notify Treasure Coast Hospice right away if you or your loved one is having thoughts of suicide

Our Complementary Therapies

In addition to our Hospice and Grief Support programs, Treasure Coast Hospice provides several complementary therapies for our patients including Music Therapy, Massage Therapy and Aromatherapy. For more information, please contact your Social Worker.

NUTRITION (FOOD & FLUID)

The desire to eat or drink at the end of life usually decreases. It is normal for the person to lose interest in food and drink as their illness progresses.

This is a natural response of the body as the organs are slowing down and it becomes difficult to manage the intake of food and/or fluids. Treatment choices will depend on the person's wishes and illness

What you can do?

- If patient is responsive and can swallow:
  - Encourage favorite foods and drinks, never force a person to eat or drink
  - Offer drinks or sips throughout the day
  - Offer small meals and use smaller dishes
  - Make mealtime a quiet and pleasant time
  - Encourage the person to rest before and after a meal
- If nausea is a problem, serve small portions of salty (not sweet), dry foods and clear liquids
- Clean the mouth often – a pleasant tasting mouth may make food taste better
- Support the person's decision if he/she refuses food and/or fluids
- Find other ways besides food and drink to show care and support. For example, offer the person a massage, apply lotion to his or her hands or feet, look through a picture album together

What to report to the Treasure Coast Hospice Team?

- Patient's inability to eat or drink or having trouble swallowing
- Has a dry mouth, tongue, or skin
- Making less urine
- Becomes confused or drowsy

SKIN CARE TIPS

Seriously ill patients may experience two common skin problems: Pressure Ulcers and chafed skin.

Pressure Ulcer (bedsore): is an area of the skin that loses its blood supply for extended periods of time. This skin reddens, breaks down, and can become painful. If left untreated, wounds and infections could develop. Bedsores can be found on tailbones/buttocks, joints (elbows, heels, ankles), back of the head, hips and spine.

Chafed Skin: Is an irritation caused by heat, moisture or friction. Chafed skin occurs in areas of the body where there are skin folds. Examples are: groin, under breasts or abdomen. It is especially important to keep these areas clean and dry.

Even with the most attentive care, patients may still develop skin problems because of their declining condition.

What can you do?

- If patient is bedbound change position at least every two hours; one hour if in a chair
  - If the patient is unable to move safely by himself/herself, you may need to help
- Use “draw” or “pull” sheets to move the patient to avoid friction from sheets
- Use warm water and gentle soaps for bathing
- Avoid friction and rubbing
- Never massage reddened areas
- Apply a lightweight lotion to the skin after bathing to increase moisture
- Keep bed linens clean, dry and free from wrinkles
- Change and apply clean absorbent pads and briefs often to keep skin dry

  - If the patient uses a bedpan or bedside commode, move the patient off after a couple of minutes to avoid pressure on the tailbone
- Never apply heat or further irritate reddened skin
- Your Treasure Coast Hospice Team can order special supplies for the patient if needed, including:
  - Special mattress to help prevent skin breakdown
  - Special Dressings
  - Skin care products (cleansers, moisturizers, barriers)

What to report to the Treasure Coast Hospice Team?

- Irritated, itching or reddened areas of the skin
- Painful, burning or tingling of the skin
- Any open wounds or new growths

URINARY CATHETER CARE TIPS

In some conditions, patients may have difficulty emptying their bladder and a catheter (a thin tube from the bladder to a collection bag) may need to be inserted.

The nurse inserting the catheter will provide instruction regarding its care.

General Care

- Never pull on the catheter or try to take it out
- Always wash hands before and after touching the catheter or bag
- Make sure there are no twists, bends or kinks in the catheter tube
- Always make sure there are no leaks in the catheter or bag
- Always wipe female from front to back after a bowel movement

Some useful actions you can take if the catheter does not seem to be draining properly:

- Check the catheter to make sure it is not twisted, pulled too tight, kinked, or under the patient
- Make sure the catheter collection bag is hanging below the level of the patient's body

Some common problems with catheters that need to be reported to the hospice nurse include:

- Burning or pain
- Sudden decrease in urine through the catheter
- Blood or mucus in or around the catheter
- Catheter gets pulled out

CAREGIVER SUPPORT

Caring for ourselves is often neglected when we are caring for another. Discuss caregiving stressors with your social worker.

10 Tips for Family Caregivers

1. Remember to **BE GOOD TO YOURSELF**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
2. **WATCH OUT** for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, **ACCEPT THE OFFER** and suggest specific things that they can do.

4. **EDUCATE YOURSELF** about your loved one's condition. Information is empowering.
5. There's a difference between caring and doing. **BE OPEN TO TECHNOLOGIES AND IDEAS** that promote your loved one's independence.
6. **TRUST YOUR INSTINCTS.** Most of the time they'll lead you in the right direction.
7. Grieve for your losses, and then allow yourself to **DREAM NEW DREAMS.**
8. **STAND UP FOR YOUR RIGHTS** as a caregiver and a citizen.
9. **SEEK SUPPORT** from other caregivers. There is great strength in knowing you are not alone.
10. Choose to **TAKE CHARGE** of your life, and don't let your loved one's illness or disability always take center stage.

PREPARING FOR THE LOSS OF A LOVED ONE

If you, or someone you love, has been diagnosed with a terminal illness, you may have many questions.

What is going to happen?

What should I do?

What should I say?

Stages of Dying

Elisabeth Kubler-Ross devoted her career to studying terminally ill patients and educating people on these questions. In 1969, her book On Death and Dying was published where she described five stages that patients and families may go through.

Today, it's widely accepted that this process does not occur in distinct stages or in a step-by-step fashion, and everyone does not experience every aspect, but her landmark work provides important insight on navigating the road ahead.

Kubler-Ross tells us that initially, a profound sense of shock and disbelief envelops the patient and family. This serves as a shield from the enormity of the situation and creates space for taking in new information and formulating a plan. At first, the prospect of death is unfathomable. This is **Stage 1**—what Kubler-Ross termed **Denial**. Today, better words to use might be shock or disbelief. What is needed most right now is kindness, patience, information and help with essential tasks.

Stage 2 is Anger. The prospect of leaving loved ones and missing out on life's pleasures can bring frustration and resentment. Questions of why is this happening and why did it happen to me fill our mind. Anger may be projected onto friends, family or medical personnel. If you are the target of this anger, try not to take it personally. Understand this is a difficult, but natural part of the process. It can really help to get these thoughts and feelings out rather than leaving them pent up inside. Allowing the patient and express his or her feelings is a precious gift, and may help to alleviate these feelings allowing passage to the next stage.

Stage 3 is bargaining where wishes are coupled with the promise of good behavior. Bargains often include the postponement of death, freedom from pain and suffering, or the chance to enjoy one last pleasure. Bargains may be made with God and may be

Treasure Coast Hospice Grief Support

Treasure Coast Hospice Grief Support counselors help adults, children and families in each of the communities we serve. Our counselors offer willing ears, an open heart and years of experience to help you find the tools you need to cope with grief and find hope and healing.

kept secret. When we are able to provide a patient with a final wish, this is a precious gift.

When the prospect of death seems certain, sorrow and quiet reflection often emerge. This is **Stage 4** - what Kubler-Ross termed **Depression**. The patient becomes less interested in everyday activities, may withdraw from family and friends and may have increased interest in what lies ahead. Kubler-Ross cautions us that efforts to provide good cheer can interfere with the emotional preparation that is occurring. She also reports that depression often lifts once important tasks have been taken care of. Therefore, completing, rather than delaying, final arrangements may offer the patient and family relief.

The final stage is **Stage 5 Acceptance**. It is neither a happy nor a sad time. The struggle is over. The patient's circle of interest diminishes. Communication is increasingly nonverbal, and silence is often preferred. Visitors may not be welcome, and sleep patterns often resemble that of a newborn child.

Use this information to guide you in caring for the patient and understanding your own experience. With greater understanding, we are better able to choose, listen, and be present when we are needed most.

Talking About Death

Perhaps the greatest gift we can give someone is to share important life experiences with them. Supporting a loved one at end of life is undoubtedly a precious gift. Talking about this can be difficult but can also be the most meaningful conversations you will ever have. If you are able, saying goodbye can eliminate the regret of not having said it. Some believe that giving the patient permission to go allows his/her spirit to be released. Knowing that you will be all right no matter what can help soothe the patient's fears about leaving.

Here are suggestions to help you prepare for these conversations:

- Start by sharing a treasured memory, or begin simply with "Thank you for being such an important part of my life."
- Meet the patient right where he or she is. Don't wait for the perfect time, because it may not come.
- Keep an open mind and let the conversation develop naturally. Avoid having a preconceived outcome.
- Be curious rather than assertive. Openly express your views, but don't impose them on others. Allow others to have their own thoughts and feelings.
- Answer questions as honesty as you can. Avoid keeping secrets.
- The goal is to share--not necessarily agree. Most people have strongly held views about death and they don't always agree with others. That's OK. Try to acknowledge all points of view.
- Welcome emotions even the difficult ones. Tears, sadness and anger are a natural part of the process. It helps to get them out rather than leave them pent up inside. Allowing the patient to express these feelings is a precious gift, and may help to alleviate them.
- Make room for silence and not knowing. Although there is much that is known about the death process, there is much more that is not. No one has all the answers. As communication becomes increasingly non-verbal, your presence is felt, heard and speaks volumes.
- Try to avoid making the patient feel guilty for leaving.

Early in the conversation, you will find the patient is either comfortable or not comfortable talking about approaching death. Some people know exactly what they are feeling and are able to express it, while others cannot. Some people hold on to important information waiting for just the right moment to share it, while others feel everything needed has been said. The only way to know is to ask. Try asking open-end questions like:

Did you know? Treasure Coast Hospice has a team of spiritual care coordinators to help provide an extra level of comfort during this difficult time.

- **What are you thinking?**
- **What are you feeling?**
- **Is there anything you need?**
- **How can I help?**
- **Who do you want to be here?**
- **Would you prefer to be alone?**
- **What would you say are your greatest accomplishments?**
- **How do you want to be remembered?**
- **What do you think happens when you die?**

With ongoing dialogue, the conversation may deepen and ideas may change over time. If the patient does not want to talk, don't force the issue. Share what's on your mind. This can open the door for future conversations. Avoid keeping secrets or pushing someone to talk.

If the patient is not able to communicate, refer to advance directives and just be present. The time to talk has passed. More than words, your presence says I love you, and I'm here for you.

Talking about death reduces miscommunication and creates a bridge between the spoken and unspoken. If you want to be sure that everything has been said, try having the conversation.

Treasure Coast Hospice Volunteers

Since 1982, volunteers have led our organization, and they continue to do so today. An integral part of our team, volunteers play many roles from visiting with patients, working with families, caring for pets to helping us with special events and community presentations.

Near Death Awareness

The patient may see people who have already died or other things you do not see. He or she may gesture in unusual ways, have vivid dreams, and make statements that seem bizarre or out of character. The patient may talk about preparing for a trip or use other symbolic language about an upcoming journey. This well-documented phenomenon is called near death awareness (NDA), and it is estimated that 50-60% of patients experience it. Many NDAs are remarkably similar including seeing deceased family members or the reaching of hands upward at the moment of death. NDAs have been associated with a peaceful death experience.[1,2,3]

Try to keep an open mind about NDA. Ask questions like "What did you see? Tell me more, or what do you think this means?" This helps to validate the patient's experience. Avoid dismissing or correcting NDA.

Additional Resources

- Visions, Trips and Crowded Rooms: Who and What You See Before You Die by David Kessler.
- Final Gifts by Maggie Callahan
- This Handout is also available as a video: https://www.youtube.com/watch?v=PGjwInM_rDc

References

1. Mazzarino-Willett A. Deathbed Phenomena: Its role in peaceful death and terminal restlessness. Am Journal of Hospice & Palliative Care 2010;27(2):127-133.
2. Adam, M & Marchand, L. Fast Facts and Concepts #118. Near Death Awareness. Retrieved 6/24/19 from https://www.mypcnow.org/blank-rnt14
3. Lawrence M and Repede E. The Incidence of Deathbed Communications and Their Impact on the Dying Process. Am J Hospice & Palliative Care 2013;30:632-639.

Treasure Coast Hospice has been awarded The Joint Commission's Gold Seal of Approval for hospice accreditation by demonstrating continuous compliance with its performance standards.

Treasure Coast Hospice

A TREASURE HEALTH SERVICE

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Thomas Counseling Center
5000 Dunn Road
Ft. Pierce, FL 34981

Okeechobee Office
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Okeechobee, FL 34972

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Foundation
(772) 403-4547

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(772) 403-4530

Volunteer Services
(772) 403-4510

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