The Hospice Care Plan

A Path to Comfort

"Care is Treatment"

Care Videos

4th Edition By

Odonata Care™

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DISCLAIMER

The information contained in this written material provides simple instructions regarding care needs and for relieving common symptoms that arise for a person during the end of their life. This information is not intended or implied to be a substitute for professional medical advice, diagnosis or treatment. All content, including text, graphics, images and information, contained within this booklet is for general information purposes only. Furthermore, Odonata Care and the authors make no representation and assume no responsibility for the accuracy of information contained in this reading material, including references to or advertisements of any products inserted on any of its pages. Such information is subject to change without notice. **NEVER DISREGARD PROFESSIONAL MEDICAL ADVICE OR DELAY SEEKING MEDICAL TREATMENT BECAUSE OF SOMETHING YOU HAVE READ IN THESE READING MATERIALS.**

Introduction

Introducing the 4 C's: Calm, Comfortable, Clean and Cared For

These are the basics to good end-of-life care. Throughout the booklet we ask you to step back and ask, are the 4 C's being met? This is a simple but important question to ask no matter what symptom or situation is being faced. It is easy to remember and keeps the care focused on a path to comfort.

MEET YOUR HOSPICE TEAM: Hospice uses a team approach to provide end-of -life care. The primary team includes a hospice physician and the referring provider, nurse, social worker, chaplain, personal care aide, and volunteer. Additional therapies may be utilized such as physical therapy, occupational therapy, or speech therapy but are used as consultants, not for rehabilitation purposes. Some hospices provide massage, music, doulas, art, and pet therapy.

Each team member contributes a set of skills and support to the patient and their care circle.

- Hospice medical provider: directs symptom management.
- Nurse case manager: acts as the hub-of-the-wheel to facilitate symptom management and coordinate the patient's care needs.
- Social worker: facilitates the psychological, logistical, and emotional needs.
- Chaplain: provides solace, explores life legacy, and serves spiritual needs and practices.
- Hospice Aide: provides personal care and assists with tasks of daily living.
- Volunteer: may provide companionship and an array of other needed services.
- Death Doula: Provides non-medical, emotional, physical, and educational support for the dying patient and family.

WHAT YOU NEED TO KNOW ABOUT THE END-OF-LIFE:

- Dying is a personal process that is experienced physically, emotionally, and spiritually.
- There are as many individual ways to die as there are to live.
- Caring for a person at end-of-life can be overwhelming and even scary, but with the help of the hospice team, people are able to die comfortably wherever they live.
- The goals of care shift from cure and rehabilitation to quality and comfort.
- People who receive good symptom management and care often live longer and remain more comfortable, with an improved quality of life.

A VIDEO IS WORTH A THOUSAND WORDS: We invite you to visit The Hospice Care Plan on YouTube for our free helpful online video demonstrations. Our video tutorials have been created to assist families and caregivers to quickly learn caregiving techniques, symptom management, and end-of-life needs for the hospice patient. Each QR code takes the reader directly to the video playlist associated with each section.

ABOUT THE AUTHORS: Our mission is to *Transform the End-of-Life Experience through Education and Support*. We do this by recognizing that *Care is Treatment*, which is our motto. The *4 C's of Calm, Comfortable, Clean, and Cared For,* is the path to good end-of-life care.

We are certified hospice and palliative nurses with over 50 years of combined hospice experience at the bedside. This booklet was born out of the recognition for the need of a hands-on / how-to-guide for the hospice patient. Our years of extensive education make us experts in our field. We are passionate nurses who serve as mentors and educators of nurses, students, hospice volunteers, and the community at large. We have immense respect and admiration for our seasoned colleagues as well as those who are new to the field. It takes a team to provide the best overall care.

Experience has taught us that we all find our way to death and we do this in the same way as we live. We hold deep compassion and respect for the patient facing end-of-life and for those who provide love and care for them. We hope this booklet and the accompanying videos help ease your way on this path. Our mission is to transform the end-of-life experience through education and support.

Brenda Kizzire, RN, BSN, CHPN **Nancy Heyerman, RN, BSN, CHPN**

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Contact List

PATIENT'S NAME AND DATE OF BIRTH: /

YOUR HOSPICE:

ADMISSION DATE TO HOSPICE:

24-HOUR PHONE (ON CALL) NUMBER:

YOUR HOSPICE TEAM:

NURSE CASE MANAGER:

SOCIAL WORKER:

CHAPLAIN:

BATH (PERSONAL CARE) AIDE:

VOLUNTEER:

HOSPICE M.D.:

PRIMARY CARE DOCTOR (PCP): PHONE #:

FUNERAL HOME: PHONE #:

POWER OF ATTORNEY: PHONE #:

POINT PERSON: PHONE #:

PRIMARY FAMILY: PHONE #:

PHONE #:

PHONE #:

PHONE #:

PHONE #:

FRIEND/NEIGHBOR: PHONE #:

CAREGIVING AGENCY: PHONE #:

CAREGIVER: PHONE #:

CAREGIVER: PHONE #:

About the Dying Body

Our human body is both a miraculous and mysterious machine. Its one job is to live and live and live some more. When it is time for this living to come to an end, the body knows how to die. Inwardly, it works to find enough physiologic balance to continue while preparing and slowing. Often there are no changes in vital signs—pulse and blood pressure—until the last few days of life, as the body continues to make its everlasting effort quietly beneath our awareness. Outwardly, there is a natural spiral of decreasing energy, wakefulness, responsiveness. The body asks for, and even insists upon, less food and water, then shrinks with that natural dehydration, which allows for deeper and longer sleep. The dying process is built into our bodies. As there is less opportunity to drink, the brain releases endorphins—our natural chemicals that produce a kind of bliss. This allows for comfort during this transition. Without fluid, we die within approximately 4–14 days, based on the amount of reserve at the start. The body wants to be quiet, so calories are no longer important or needed. We all store enough fluid and calories in our fat and muscles to keep the balance of energy needed while dying. The kidneys filter and balance all of the important elements in the blood. The breath slows and changes, decreasing the amount of oxygen our bodies can take in and absorb. At the same time, our life bubble is also shrinking and detaching from life and our loved ones. As this natural state of withdrawal and dehydration advances, decreased oxygen, calories, and fluid work in conjunction to lead our bodies to their inevitable end.

HOW MUCH TIME IS LEFT? It is well known that the health care team is not good at guessing how much time a person has left to live. It is true we don't know how long a person has to live, but this guide can assist in estimating where the person is on their life continuum. What we know is that when someone is declining monthly, they tend to have months left to live. The same is true for both weeks and days and even down to hours and minutes. If you see them becoming weaker, eating less, being less active over the period of a month or more, they probably have months to live. If the decline has become more rapid and now the changes are noticeable weekly, then likely only weeks remain.

Please refer to the pages on TRANSITION AND ACTIVE DYING, which generally describe the last 2-3 weeks of life. It's true we don't know how long a person has to live. But this guide can assist in estimating where the person is on their life continuum. Hopefully this can help you see more clearly which end-of-life stage the patient is experiencing. Knowing this information can allow for less anxiety and the ability to stay focused in the present moment, while planning for life going on around you.

In the final weeks to days, people generally need 24-hour care, because they can no longer care for themselves. Often the vigil during this last stage is the hardest overt work for the care circle. The waiting game can be both a trial and a blessing, as family members reminisce and reconnect over the loved one's sleeping form or work together providing the actual bed care. There is no rush…we only die once, and everyone finds their own individual way.

ABOUT SYMPTOM MANAGEMENT: Well-managed symptoms are essential to facilitate the most compassionate and peaceful end-of-life process. This allows the remaining energy to be on spent living life. Our goal in writing this booklet is to provide the patient and family with the tools and knowledge to keep people calm and comfortable in the dying process. Not knowing how to safely and effectively relieve someone's symptoms can be distressing for everyone. It can be traumatic to witness the unmanaged suffering of a loved one.

Try to identify and focus on the symptom that is present, such as pain, anxiety, or shortness of breath, and then turn to that page. Taking the time to read and implement the suggestions will empower the family and caregiver to provide superb care to the dying patient. The path is never perfect; there will be ups and downs. But with the guidance of this booklet, our videos, and your hospice team, the chance of having a compassionate and peaceful death is more attainable.

Medication Management

GOALS:

- To use the right amount of medication to achieve the desired effect, which provides the best quality of life possible.
- To successfully and with confidence administer or take medications.

WHAT TO KNOW:

- The patient is not dying because we are giving medications; medications are given because the patient is dying.
- Addiction is NOT an issue at the end-of-life.
- Discomfort can rob you of your life energy.
- There can be fear and concern about taking and giving medications.
- Managing and organizing medications can be one of the biggest challenges.
- People can live longer and better with good symptom management.
- Less medication is often needed when symptoms are prevented and treated quickly.
- PRN is a Latin abbreviation referring to as-needed medications. The hospice team may use this term.
- It can be expected that hospice will account for opioids in the home.

ABOUT MEDICATIONS:

- The comfort medications prescribed are designed to work well together. Interactions are reviewed for safety.
- There are many routes to administer medications: oral, sublingual (under the tongue), rectal, and injectable.
- These medicines are simply tools in the toolbox and will only be used if needed.
- Everyone responds differently to medications.
- It can take trial and error to find the right amount and combination of medications for the most effective symptom management. When starting a medication, start low and go slow.
- Giving small routine doses of medications avoids the rollercoaster of discomfort.

MEDICATIONS OFTEN USED FOR COMFORT:

New generations of comfort medications are continually being developed. Options may vary between hospices.

- Opioid medications commonly used for pain and/or shortness of breath:
  - MORPHINE
  - OXYCODONE
  - METHADONE
  - HYDROCODONE
  - DILAUDID
  - TRAMADOL
  - BUPRENORPHINE
- Medications generally used for anxiety or agitation and nausea:
  - LORAZEPAM (ATIVAN),
  - HALOPERIDOL (HALDOL)
  - VALIUM (DIAZEPAM)
- The hospice nurse and doctor have expertise in using these medications.
- Being open to their suggestions will likely achieve comfort more quickly.

SEE Forms for Routine and As-Needed Medication Use on Page 6.

Medication Management

WHAT TO DO:

- Care is Treatment! Always meet their basic care needs first. Avoid waiting too long for use of comfort medications.
- Take routinely scheduled medications consistently for maximum benefit.
- Use the as-needed or PRN medications for breakthrough symptoms not managed by your routinely scheduled medicines.
- Keep track of the as-needed or PRN medications:

See Medication Forms, starting on the next page.

- Write their usage down using the form included in this booklet, or any system that works for you, as long as the nurse can review it.
- The nurse, with orders from the hospice doctor, uses this information to adjust and manage the medication regimen.
- Request medication refills at least 48 hours prior to needing more.

MAKE A SAFE SPACE TO MANAGE AND ORGANIZE MEDICATIONS:

- Clear an area that is large enough for all the medications and is easy to access, near the patient.
- Consider using a towel or large sheet of paper to provide a defined and clear surface.
- Organize your medications into routine scheduled medications and those for as-needed use.
- A pill box or mediset works well for scheduled medications. You or the hospice nurse can refill, usually once a week. This will help avoid running out of medications.
- Safety is very important. Keep out of reach of children and pets.
- A lock box may be needed for anyone with addiction challenges who has access to the medications.

HOW TO USE LIQUID MEDICATIONS:

- Hospice uses medications which are concentrated so only a small amount is needed.
- The medication is placed anywhere in the mouth, generally outside the teeth toward the back between the cheek and the gum. It does not need to go under the tongue.
- Because they are concentrated, there is no need to worry about swallowing.
- Moisten and clean the mouth with the oral sponges before giving liquid medications.

HOW TO USE BOTH PILLS AND LIQUIDS TOGETHER:

- When using both liquid and pill form of medication, crush the pill and dissolve in the liquid medication. This allows for less fluid volume. The hospice nurse will teach you how to do this. There are a lot of right ways.

Visit TheHospiceCarePlan on YouTube to view videos for medication management.

Visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Medication Management

SCHEDULED MEDICINES			TIME				PURPOSE
Name	*Strength*	*Dose*	*Morning*	*Midday*	*Evening*	*Bedtime*	*What is it for?*

PRN / AS NEEDED MEDICATIONS - Document the use of these medications on page 7

Medications/Bowel Movement Tracking

PLEASE DOCUMENT ANY AS-NEEDED OR PRN MEDICATIONS GIVEN			BOWEL MOVEMENTS	
Date & Time	*Medication Given / Amount*	*Reason / Result*	*Date & Time*	*Amount / Quality*

Anxiety and Agitation

GOALS:

- To recognize and manage the signs of emotional and physical anxiety and agitation.
- To enjoy adequate and consistent sleep.

WHAT TO KNOW:

- Anxiety and agitation are normal, expected, and healthy responses to facing end-of-life.
- Anxiety can be very subtle and difficult to recognize.
- Anxiety can be worse than pain and is sometimes not well-managed.
- Pain and anxiety often feed off each other and may need to be treated simultaneously.
- Loss of mental ability with forgetfulness, periods of confusion, and even hallucinations, are normal and expected, but can be distressing for patients and families.
- Sleeping pattern disruptions and disturbances often arise in the end-of-life process and can cause problems during normal waking hours.
- Social workers and Chaplains are trained and skilled in providing support for emotional and spiritual concerns. Their guidance assists in reducing anxiety.

SIGNS OF ANXIETY:

- Talking about the same subject over and over: looping and obsessive thoughts.
- Looking "worried" with a furrowed brow and physically tense.
- Increased difficulty tracking conversations with decreased memory.
- Not being themselves: quiet, withdrawn, irritable, crying, fretting, increased confusion.
- Not sleeping consistently during the night.

SIGNS OF AGITATION:

- Can't sit still, restless, pacing, or unable to stay positioned in bed or chair for more than 5 minutes.
- Calling out repeatedly, reaching, trying to sit up.
- Having hallucinations or dreams that are distressing.
- Wandering in the home and falling.

WHAT TO DO:

1. ***Ask questions, stand back, and look:***
    - Do they need to pee or have a bowel movement? This is often the #1 cause.
    - Do they have a dirty brief?
    - Is there worry about something?
    - Is something needed—are they hungry or thirsty?
    - Are they too hot or too cold? Are their clothes and bedding bunched up or binding?
    - Are they uncomfortable? Often agitation and anxiety can be due to pain that can't be verbalized.
    - Are they sleep deprived?
2. ***Patiently sit, listen, and ask open-ended questions:***
    - Give time for difficult, scary thoughts or feelings to arise and be spoken.
    - No need to fix things. People just want to be heard and affirmed.
    - Repeat what you are hearing and ask for clarification: *"Tell me more..."*
    - Use the opening phrases:
      "I wish this wasn't so hard for you."
      "I worry that it's affecting the time you have left."
      "I wonder if you want to talk about anything now."
    - You may never discover what is causing their anxiety and agitation, but it is important to give the opportunity to explore and deepen the conversation.
3. ***Medications:*** When the interventions above haven't worked, it is time to give the medications instructed by your hospice team. Please do not wait too long to do this. Like pain, the goal is comfort, and sometimes a regularly scheduled medication is necessary to obtain and maintain calm.

Call hospice if you have done the above and they still aren't calm and comfortable.

Individualized Instructions for Anxiety and Agitation

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared For***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Bladder: The Need to Pee or Urinate

GOALS:

- To urinate normally and naturally and to prevent or manage problems which arise.

WHAT TO KNOW:

- Incontinence and the inability to urinate are common and expected issues.
- It is not uncommon that patients can't empty their bladder fully.
- Losing the ability to manage urination can be distressing, both emotionally and physically.
- Not wanting to wet oneself can be very distressing and can prevent the patient from wanting to use an absorbent brief.
- The inability to urinate is extremely uncomfortable and is often the cause of restlessness and agitation. Just think about a time you haven't been able to pee.
- The amount of urine will decrease and get darker in color as people drink less. This is normal, and there is no need to worry.
- Symptoms of a urinary infection (UTI) are not uncommon as the body declines. Unless the symptoms are uncomfortable, no treatment is needed.

WHAT TO DO:

1. Help them to the toilet or commode regularly at least 3X/day and as needed. This can help prevent incontinence, anxiety, and agitation. When incontinence occurs, treat in a matter-of-fact manner.
2. Genital or "peri-care" should be performed daily with or without a catheter. Gather needed supplies: Gloves, wipes, disposable or washable underpads, absorbent briefs: Use pull-up briefs when still active, tabbed briefs when bedbound.
3. When using briefs or absorbent pads, check every 2-3 hours and change when wet to protect the skin and maintain comfort. Use a thin layer of barrier cream or ointment to protect the skin. Go to for video demonstration on changing a brief.
4. ***Are they agitated and restless?***
   - When did they last pee?
   - If longer than 12 hours, maybe they can't, or if every 30 - 60 minutes, they may be retaining urine.
   - Call hospice, as a urinary catheter might be needed.
   - This can seem scary, but is often more comfortable for both the patient and caregiver.
   - Don't wait until the end of the day to report this problem.
   - Hospice wants you to call sooner rather than later to prevent problems.
5. ***Daily Catheter Care:***
   - Wash the entire genital area gently and the catheter thoroughly and daily with soap and water or wipes, and after each bowel movement.
   - Hospice will anchor the catheter to the upper thigh when it is inserted.
   - Make sure the catheter stays anchored. Pulling or tugging on a catheter that isn't secured can cause pain and possible bleeding.
   - Consider placing the catheter bag in a basin, bowl, or bucket to avoid spills.
   - White sediment seen in the tubing and bag is normal. If urine is flowing, there is no need to worry.
   - With certain diseases or if the catheter has been inadvertently pulled or tugged on, you may see blood in the tubing or bag. Again, if urine is flowing, no need to worry, but perhaps encourage increased fluid intake.
   - Leaking around the catheter may occur, but if the patient is comfortable, place an absorbent brief on them and notify your hospice team during business hours.
   - Empty the bag daily and as needed. No need to measure the amount of urine.
   - Inspect the tubing after each turn or repositioning to assure there are no twists or kinks in the catheter. This is the #1 reason for no urine flow.
   - If there is no urine in the tubing or the bag, check again for twists or kinks and reposition the patient.
   - Still no urine, and they are uncomfortable? Call hospice.

Individualized Instructions for Bladder Comfort

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Bowel Movements (BM)

GOALS:

- To prevent constipation and have a comfortable bowel movement at least every 3 days.

WHAT TO KNOW:

- If the bowels aren't working, it affects every system in the body and adds to discomfort.
- Everyone has their own regular bowel pattern.
- As the body slows and changes, so do the bowels.
- Even if you are not eating, your body still makes stool. That is why the hospice team will continue to track and confirm bowel habits.
- Disease process and medications also affect the bowels.
- It may take time to clear constipation and find the system which allows for comfortable and regular BMs.
- Hospice nurses are the best at managing bowels.
- In the active dying process, do not worry about a bowel movement unless there is discomfort.
- Incontinence is a normal issue that usually has to be faced.
- Some comfort medications cause constipation. This is expected and will be managed by hospice.

MOST COMMON BOWEL MEDICATIONS USED ON HOSPICE:

Your hospice nurse will give you personalized instructions.

- SENNA tablets - a vegetable laxative for softening and stimulation
- MIRALAX powder in any fluid or food (water, juice or even coffee)
- BISACODYL tablets - for stronger stimulation
- BISACODYL Suppository - works directly in the rectum for stimulation and lubrication

WHAT TO DO:

1. Take your prescribed bowel medication to prevent constipation.

2. If no BM by bedtime of day 2, take the next step in the bowel program.

3. If no BM by noon on day 3, call hospice for further instructions.

4. When incontinence care is needed, gather these supplies: gloves, wipes, disposable or washable underpads, and absorbent briefs: use pull-up briefs when still active, tabbed briefs when bedbound.

Use the form on page 7 to document the bowel movements. This helps the hospice team manage symptoms.

Individualized Instructions for Bowel Function and Comfort

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Breathing

GOALS:

- To breathe easily without increased effort or discomfort.
- To have quick relief from breathing difficulties.

WHAT TO KNOW:

- If anyone has to think about their breathing, something is wrong.
- Do you think about your breathing? Probably not… If your loved one is having to think about their breathing, an intervention is needed.
- Shortness of breath can be distressing and scary and will need to be addressed.
- Shortness of breath can be a subtle to dramatic experience.
- When we can't breathe, our body's response is to become anxious.
- Pain and discomfort can cause shortness of breath.
- Simple breathing techniques can calm your anxiety as it eases your breathing.
- Medications are the fastest and most effective way to relieve shortness of breath.
- Preventing breathing problems is better than treating a breathing crisis. Take routine and prn medications to achieve this.
- During active dying, a drop in the oxygen level is expected and is generally not uncomfortable to the patient. That is why it is important to look at the patient, not the oxygen number. Treat for comfort, not the number.
- Oxygen support is generally not needed, as long as breathing is comfortable.
- If oxygen is in use, it is imperative to follow all safety instructions given by your hospice team.

WHAT TO DO:

1. ***PAY ATTENTION AND LISTEN:*** If they mention their breathing, they may be struggling to breathe.
    - Count how many times they are breathing per minute.
    - If it's more than 22-24 breaths/minute, they may be working too hard.
2. ***STOP ANY ACTIVITY AND REST.***
3. ***POSITIONING IS IMPORTANT.***
    - Patient should sit upright, leaning forward if possible.
    - Perhaps rest arms on a table or a pillow.
    - If too weak to sit up, pull up in bed so that they are bent at the waist.
    - Use pillows to prop elbows and arms up and away from the body. This gives the lungs the most space possible.
    - Simple breathing techniques, such as counting as you breathe in and out, can help get control of breathing discomfort.
4. ***IF USING OXYGEN***, make sure it is set on the correct amount and assure there are no kinks in the tubing.
    - Know your parameters from hospice—if OK to turn it up, do so.
    - Oxygen safety:
        - Notify of oxygen use by posting a sign in the window for neighborhood safety and emergency services awareness.
        - No open flames in the home, such as candles, smoking, gas stoves, and fireplaces.
5. Directing a fan toward the patient can give relief.
6. If a nebulizer is part of the treatment plan, use it now.
7. ***MEDICATIONS:*** Follow your hospice's directions.
    - Make sure the patient is taking their routine medications to prevent a breathing crisis.
    - Use the as-needed or PRN medications for labored breathing.
    - You may need to repeat and use a combination of pain and anxiety medications to effectively relieve shortness of breath.
    - These medications can cause sleepiness, but don't worry, this allows for rest.
8. ***RECOVERED?*** Excellent, everyone can go back to getting the most out of their day.
9. ***NO IMPROVEMENT?*** Take a big deep breath (if possible) and call hospice.

Individualized Instructions for Breathing Comfort

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Eating, Drinking, and Swallow Precautions

GOAL:

- Full enjoyment of eating and drinking with safe comfortable swallowing for as long as possible.

WHAT TO KNOW:

- Appetite and ability to eat, drink, and swallow changes and declines as the body changes.
- The desire to eat and drink will decrease. The moments of appetite are often fleeting.
- Calories are not important. Safely eating and drinking what is enjoyed, is.
- Losing this ability can be distressing for patients and families because we eat to live, and it is how we show love.
- The patient gets to eat and drink any thing they want, when they want it.
- If they don't want to eat or drink, this is normal and expected.
- Constipation is one of the most common causes of poor appetite.
- Dehydration is an expected and normal part of dying. The use of IV fluids may cause discomfort during the dying process. The dying body likes to be dry and quiet.
- At some point they will not be able to swallow food, fluids, or medications. Hospice will provide and demonstrate how to administer comfort medications.

WHAT TO DO:

1. ***OFFER:*** Appropriate food and fluids as long as they continue to be interested and are able to swallow safely.
    - It's OK to offer and encourage but PLEASE do not push or force. Love with touch instead of food at this point.
2. ***YOUR JOB*** is to give the patient what is wanted as soon as possible.
    - Often, an urge to eat or drink is short-lived.
    - Be aware, once they are served, just a bite or sip may be all they want.
3. ***PREVENTING SWALLOWING PROBLEMS:***
    - Position to sitting. Pull up in bed so that the patient is bent at the waist.
    - Wake up the tongue. This muscle is responsible for safe swallowing.
    - Ask them to stick out their tongue at you or sing, "La la la la."
    - Wet their whistle with just a sip of fluid. It will moisten the mouth and let you know how well they can swallow.
4. ***SAFE SWALLOWING TIPS:***
    - Use a straw or sippy cup.
    - Tip the chin toward the chest while swallowing. You may have to assist patients as they weaken.
5. ***GIVE SOFT FOODS*** in small bites: applesauce, pudding, yogurt, ice cream.
    - If pills are getting hard to swallow, put them in a spoonful of a soft food, perhaps one at a time.
    - If pills are still unable to be swallowed, ask your nurse which pills may be crushed and add the medication to a spoonful of soft food.
    - ***GIVE THICK FLUIDS*** such as smoothies or milk shakes. A thickening powder may be added to water or thin juices, which makes it easier to swallow.
6. ***STOP IF THERE IS COUGHING, CHOKING, OR THEY TURN THEIR HEAD AWAY.***
    - This is the body's message, "I don't want more."
7. ***THIS MAY BE THE TIME*** to use oral sponges on a stick that hospice provides.
    - Dip the sponge into water or their favorite drink— even coffee, wine, or beer.
    - Their mouth will feel fresh as they taste what they have always enjoyed.
    - A mixture of water, mouthwash, and a few drops of any edible oil (olive, canola, etc) works well to freshen, clean, and maintain a moist mouth.

Individualized Instructions for Eating and Drinking

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Nausea, Vomiting, and Queasiness

GOALS:

- Rapid and sustained relief from nausea (sick to one's stomach).

WHAT TO KNOW:

- Nausea can feel more miserable than pain.
- It can cause depression, weakness, and even hasten death, if it inhibits drinking fluids.
- Constipation is a common cause of nausea and vomiting.

WHAT TO DO:

1. ***INVESTIGATE PRESENCE AND CAUSES OF NAUSEA BY ASKING QUESTIONS:***
    - Is there a decreased interest in food and fluids?
    - Is there queasiness, gagging, vomiting, or dry heaves?
    - When was the last bowel movement. If no bowel movement in three or more days, this may be the cause. Call your hospice team to review the bowel program.
    - Review recent foods and medications. Is there a pattern with nausea after eating or taking medications?
2. ***IF NAUSEATED:***
    - Sit patient upright and have a basin, bowl, or bag at hand.
    - Have patient sip on room temperature ginger ale, cola, ginger or mint tea.
    - Hold off on eating until the nausea has passed.
3. ***IF NO RELIEF OF NAUSEA with the above remedies:***
    - Give medication as instructed by the hospice nurse.
    - There may be need to take routine anti-nausea medications to prevent nausea.
    - Some medications are given rectally to treat nausea.
4. ***IF VOMITING:***
    - Don't try to stop the vomiting—allow it to finish.
    - Do not give anything to eat or drink for at least 30 minutes.
    - Call the hospice nurse if vomiting continues.
5. ***REPLACING FLUIDS***:
    - Give 1 tablespoon of any clear liquid and wait 30 minutes.
    - IF OK and tolerated the fluid: Give 3 tablespoons and wait 30 minutes.
    - Still OK? Then allow slow sipping as the patient desires.
    - If nausea or vomiting returns: Stop, do not give anything more and consider repeating the nausea medications.
    - Call hospice if unsure.
6. ***PREVENTING NAUSEA:***
    - Keep bowels regular.
    - Eat small, frequent meals.
    - Stay upright an hour after eating.
    - Take nausea medication 30 minutes prior to eating and drinking or before taking the medications that caused the nausea.

Individualized Instructions for Nausea Relief

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Pain and Discomfort

GOALS:

- To recognize and manage pain and discomfort.
- To effectively and safely provide interventions for consistent comfort.

WHAT TO KNOW:

- Pain is different for everyone.
- Pain consumes the energy that can be used for living well.
- Many people don't recognize pain, but patients often live with discomfort.
- Pain and anxiety often feed off each other and may need to be treated simultaneously.
- Pain may not be just a physical experience. There can be emotional, spiritual, and existential pain, expressed physically.
- Fear of pain and medications may be bigger than the pain itself.
- Good pain management includes a full pallet of medication options, which target the pain response from many different angles.
- Long-acting opioids are often taken routinely, with quick and short-acting opioids for breakthrough pain. This regimen is a hospice and palliative care standard.
- The patient may say they are in pain, yet show no outward signs.
- A patient can look fully comfortable when not moved or touched. But as care is needed, they may demonstrate pain, resist care, and even become combative.
- Expect patients to be in pain when remaining in one position for too long.
- When the patient can't communicate, families and caregivers are responsible for recognizing and treating the pain.

SIGNS OF PAIN:

- Complaining of pain and/or moaning.
- Grimacing (furrowing of the brow) and generalized tension.
- Posturing: curled into a ball, knees drawn up, guarding, clenched hands, curled toes.
- Restless, agitated, and irritable or completely shut down.

WHAT TO DO:

- Ask how they are feeling and if they are comfortable. Honor what is said, even if you don't see what has been described.
- Reposition for comfort.
- Be creative: use pillows, props, music, massage, distractions. Note what works.
- Consider medications if the patient is not comfortable after 5-10 minutes of care interventions.
- Social workers and Chaplains are trained and skilled in providing support for emotional and spiritual concerns. Their guidance assists in reducing pain. Request a visit and be open to their suggestions.

MEDICATION FOR PAIN AND COMFORT:

- Give routine medications prescribed by your hospice team.
- Use the PRN (as-needed) medications to provide comfort when the pain breaks through.
- It is important to write down the as-needed medications used on the medication form, page 7.
- Your hospice team will need this information to adjust the pain medication regimen.
- Give pain medication 20-30 minutes prior to care and activity.
- Consider using anti-anxiety medication with the pain medicine if there is a component of anxiety contributing to their discomfort.

DO NOT WAIT:

Please call hospice if unable to get the patient comfortable. Hospice is available 24 hours a day to help manage pain and other symptoms that are not adequately relieved.

Individualized Instructions for Pain and Discomfort Relief

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Secretions and Gurgling in the Active Dying Process

GOAL:

- To support and educate the family and caregivers during the active dying process when the sounds of breathing change and the patient is no longer able to swallow.

WHAT TO KNOW:

- It is normal and expected that a patient will lose the ability to swallow in the active dying process.
- Saliva collects at the back of the throat because the patient can no longer swallow. It causes a wet gurgling sound when breathing in and out as the air passes over the fluids.
- The sounds of breathing can be distressing for families.
- There are fewer breathing issues if a patient has entered the active dying process following the body's desire not to eat and drink.
- Dehydration is normal and serves the body best by providing the most comfort during the dying process.
- In the past medications were used to manage oral secretions but studies now show these are generally not helpful and are no longer commonly used.
- The best intervention for managing secretions is consistent oral care and positioning.

WHAT TO DO:

BE PROACTIVE AND BEGIN GOOD ORAL CARE BEFORE SECRETIONS BECOME AN ISSUE. This is a comfort measure that helps prevent the build-up of secretions and dried saliva.

1. ***GATHER NEEDED SUPPLIES:*** Mouth swabs (a sponge on a stick provided by hospice), fresh glass of water, mouthwash, tissues or washcloth, and lip balm.
2. ***ORAL CARE:***
   - Swab the mouth every 2-3 hours and before giving medications. A mixture of water, mouthwash, and a few drops of any edible oil (olive, canola, etc) works well to freshen, clean, and maintain a moist mouth.
   - Start with the lips, roll into the mouth, and swab along the outside of the teeth. If the patient allows, roll into the inside of the mouth and swab the tongue and roof of the mouth.
   - Consider this a substitute for brushing the teeth.
   - Liberally apply lip balm.
3. ***REPOSITIONING TO CLEAR SECRETIONS:***
   - Place a towel under the patient's head.
   - Try turning their head gently several times. This may stimulate a swallow and naturally clear the secretions.
   - For excessive secretions, follow the next two steps.
   - Flatten the top of the bed and raise the foot of the bed. Gravity will help. Then turn the patient far to their side, almost to the tummy.
   - The secretions may run out or they will move to the mouth where they can be removed.
   - Use a dry mouth swab to help pull out the secretions. Don't be afraid to go deep into the mouth.
   - Don't fret if they clamp down on the sponge— just wait and their jaw will relax.
   - If swabs are unavailable or not enough, wrap a dry washcloth around your finger to sweep out the mouth.
   - This can be intense but brief and can resolve the problem.
4. Once clear, reposition with the head of the bed slightly raised.
5. A humidified room can help keep the mouth moist.
6. Call hospice if your efforts haven't helped.

Skin and Wound Care

GOALS:

- Maintain skin integrity as long as possible.
- Provide containment and comfort for any breakdown of the skin that does occur.

WHAT TO KNOW:

- Skin is the largest organ of the body. As end of life approaches, skin becomes fragile.
- Skin breakdown may not always be avoided, but prevention is the best comfort measure.
- When there is pressure on the skin too long—from lying in bed or sitting still in one position—lack of blood flow in or out causes the skin to break down.
- In the dying process, skin will change (sometimes drastically), including color, moisture and temperature.
- When skin begins to become fragile and breakdown, this may be an indication that the patient is in transition.

WOUND CARE INSTRUCTIONS:

Hospices generally provide dressings, bandages, and supplies that offer containment and comfort for wounds.

WHAT TO DO:

- Assess for red spots, scrapes, bruises, dryness, rash and odors. Notify your hospice nurse if you identify any of these problems.
- Care for their skin as you would yours—keep it clean and dry.
- The skin needs to be thoroughly cleaned and moisturized. Don't be afraid to firmly clean, touch, and massage. Use their favorite products: oils, lotions, fragrances. This is a comfort measure.
- At least 3 pillows or props (rolled up blankets or towels) are needed to provide comfortable positioning.
- Change the position every 2–3 hours during waking hours and at least once during the night to prevent skin breakdown from pressure.
- Even heavy blankets on the toes can cause breakdown. Create a "bed cradle" to lift the covers off the toes by placing a large pillow or box at the end of the bed.
- Heels take the full weight of the leg and can quickly break down. Support the heels by placing a pillow under the calves, between the knee and the ankle. This is called "floating the heels".
- Turning and repositioning help prevent or minimize skin breakdown, but can be uncomfortable for the patient, so medicate for comfort.
- If skin is cool to the touch, comfortably cover the patient.
- If warm or hot and sweaty, remove blankets and wipe the skin with a warm, moist cloth. As it dries and evaporates, it will cool the skin.
- Use a fan on low setting if it improves comfort.
- These interventions are adequate to keep the skin comfortable.
- Medications to reduce fever are not needed in the active dying state.

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Personal Care and Safety

GOALS:

- To provide safe, loving care when the patient is no longer able to care for themselves.
- To follow guidelines and use techniques that will help prevent injuries to patients and caregivers.

WHAT TO KNOW:

- Losing faith and trust in one's body to function normally as it always has, is one of the greatest challenges in facing the end-of-life.
- It's a very human experience to expect we can do more than our declining bodies actually can.
- Due to declining physical and mental abilities, simple daily tasks take longer to accomplish.
- Valued pride and independence may inhibit a patient from asking for assistance.
- This is the most potentially dangerous time for injury due to falls.
- Expected mental changes may prevent a patient from knowing or remembering to ask for help.
- Giving comfort care to a loved one can be scary when you don't know how to do it.
- Bedrails are often used for safety and to assist movement in bed; the purpose is not for restraint.
- Hospices provide bath aides to assist with bathing and personal care.
- Death doulas are sometimes part of the care team offering nonmedical end-of-life support.
- Visitors can be helpful but can also add emotional stress and fatigue to both the patient and family.

WHAT TO DO:

BE PROACTIVE AND BE PATIENT

- Always allow the patient to do as much as they are able without interference.
- Step back and let them be as long as they are safe. This is much harder than it sounds.
- Notice activities that are beginning to be more difficult for them to accomplish: standing up, walking with balance, feeding themselves, managing the toilet, and personal bathing care.
- Having the hospice aide invited sooner than later allows for familiarity. It can be as simple as starting with a foot rub.
- It's OK and encouraged to ask family, friends, and volunteers to help with chores and errands on a scheduled and recurring basis.
- If you feel the need for more support, consider hiring a death doula or caregiver. Your hospice social worker can assist.
- Have the appropriate equipment in place sooner rather than later. Discuss the needs with your hospice nurse: walker, wheelchair, commode, shower bench, hospital bed, and over bed table.
- Even if the patient is not emotionally ready to accept the equipment, get it delivered and store it out of sight if possible.
- Ask for help to rearrange the patient's room for ease of care and improved safety of the patient and caregiver.
- Obtain personal care supplies before needed, if not provided by hospice: gloves, wipes, absorbent briefs, and bed pads.
- If bedrails are being used, encourage the patient to use them to help with turning and positioning.
- Bedrails may be lowered when caregiving is needed. Make sure to raise for safety when finished with care.
- Raise and lock the bed before care to protect the caregiver. Remember to lower the bed when care is complete.
- This work is much harder than people realize. Take care and be kind with yourself.

A VIDEO IS WORTH A THOUSAND WORDS:

Use the QR codes for each section to view our videos demonstrating personal care, end-of-life education, and support.

Patient Preferences and Notes

Are the 4C's being Met? ***Calm, Comfortable, Clean and Cared for***

Use the QR code to visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Transition into Dying

GOALS:

- To recognize and understand the signs of transitioning into the dying process.
- To keep the patient safe and honor the 4 C's: Calm, Comfortable, Clean and Cared For.
- To obtain needed support and equipment during this time of escalated care needs.

WHAT TO KNOW:

Changes begin to occur more rapidly during the transitional process.

- The transition process usually lasts 4–14 days, but this can vary widely; the patient may even float between full alertness and active dying. Because the swings can be so acute and broad, be patient with them and yourself.
- Transition is often the most difficult period of the dying process as patients realize they are losing their grip on the body and mind as their life bubble shrinks.
- Leaning into what the transitioning body wants and doesn't want is easier on the patient and escorts a smoother active dying process. There may be ups and downs from day to day and even hour to hour. Go with the flow.
- As a person is declining they lose energy, mental acuity, and physical capacity. They start detaching from life around them.
- Due to the decline in ability there is an increased loss of personal control that can be distressing and anxiety producing.
- It is a normal human trait to think we can do more than our body is able to as we weaken into the dying process. There is more risk for falls and injuries at this time, so more vigilance in care is needed.
- The need to communicate diminishes at the same time the swallow and voice weakens. This assists in letting go and detaching from life. This is healthy, normal, and expected.
- If the patient has an implanted pacemaker with a defibrillator, the hospice team will coordinate deactivation of the defibrillator portion of the pacemaker.
- This is the time to call family and friends, if appropriate for final visits or conversations.
- Pets are not only cherished family members, but often have the most intimate connection to the dying person. You may see changes in the pet's behavior as the patient is transitioning. Allow their presence in the room and even in bed with the patient if appropriate.

SIGNS OF TRANSITION:

Be observant of your patient or loved one, as the signs of transition arise differently with each individual.

- There will be Increased sleeping and patterns of sleep may change. It is not uncommon for days and nights to be confused.
- Appetite will decrease, with less interest and desire for food and fluids, along with difficulty swallowing.
- Expect mental changes such as forgetfulness, possible confusion, being less engaged in TV, reading, conversations, and phone use.
- This is often a time of increased dreaming and life review.
- Anxiety may begin with restlessness and irritability.
- Agitation may present itself with reaching, unsettled behavior, or inability to sit or lie still.
- Transition is often the start of incontinence and changes in both bowel and bladder habits.
- Expect an increase in weakness and imbalance. The ability to get in and out of a chair or walk independently diminishes. This is when falls are most likely to occur.
- The potential for skin breakdown is now higher.

WHAT TO DO:

- Patients need increased caregiving during transition and should no longer be left alone at this time. See Personal Care and Safety videos.
- Arrange for increased caregiving needs, in advance if possible. This may include: family, friends, neighbors, doulas, and hired caregivers. The hospice social worker can assist with this.
- If family is unable to visit, consider phone or video visits at an appropriate time.
- Do not take it personally when you feel them pulling away; this subtle shift is normal and necessary.
- Expect and allow for increased sleep.
- Honor what patients want and don't want to eat and drink. Food and fluids are no longer important. It is often hard for families and caregivers to accept this. You may offer and gently coax, but don't push or force.
- Assess for safe swallowing and adjust foods and fluids as needed. See Eating and Drinking.
- Expect incontinence and treat in a "matter of fact" manner and have products available. See Bowel and Bladder.

Active Dying

GOALS:

- To recognize the signs of an actively dying patient and to know when death is imminent.
- To offer a calm and peaceful space for the patient to die in a comfortable and dignified manner.

WHAT TO KNOW:

- The active dying process generally lasts 1-3 days, but this can vary.
- The body's appearance can drastically change in the dying process.
- The body and all its organs are slowing down and losing their functions.
- Skin temperature and appearance can drastically change in the dying process. Use of medication is not needed and would be invasive at this point.
- Dehydration is an expected and normal part of dying. The use of IV fluids may cause discomfort during the dying process. The dying body likes to be dry and quiet.
- Expect breathing changes. This can cause anxiety in those caring for the patient, but it is natural and expected.
- The presence of a pacemaker during active dying will not cause discomfort or extend a patient's life.
- This time can be physically and emotionally intense for patients, families, and caregivers, but also rich, deep, and beautiful.
- Loved ones can have an emotional shift into acceptance and even feel relief as death approaches. Anticipatory grief is healthy.
- Allow space and accept each family member's ability to be present in their own manner, or not present at all, during the active dying process.
- A calm, peaceful space helps to promote a comfortable death, and sets the stage for acceptance and healthy bereavement.
- Hospice functions as a team. Each member offers a different set of skills to meet the physical, emotional, and spiritual needs of the patient.

SIGNS OF ACTIVELY DYING:

- Patients are now fully bedbound and are generally not waking up.
- Eating and drinking has ceased and they are losing their ability to swallow.
- They can no longer take their routine medications, but only the concentrated comfort meds.
- They are incontinent of bowel and bladder and frequency of both have dramatically decreased.
- Turning themselves in bed is no longer possible and they must rely on others to keep them clean, comfortable, and safe.
- Changes in depth and rhythm of breathing are apparent, with an open mouth and slack jaw.
- Breathing patterns change and there are often pauses in the breath lasting up to 45 seconds.
- Oxygen levels will decline, generally without any sign of discomfort.
- The heart rate will become weak, rapid, and possibly irregular. You may not be able to feel pulses in the extremities.
- Skin may become pale, gray, cool, clammy, and appear mottled or bluish.
- As dehydration deepens, the body appears to shrink and the bones become more prominent.

WHAT TO DO:

- Continue the turning schedule of every 2-3 hours during waking hours and once or twice during the night.
- Keep the mouth clean and moist. See Secretions.
- If patient's skin is cool to the touch, comfortably cover them. If warm or hot and sweaty, remove blankets and wipe the skin with a warm, moist cloth. These interventions are adequate to keep the patient comfortable.
- Continue bath aide visits. They are skilled at providing this gentle care.
- Maintain the routine comfort medication regimen set by your hospice team.
- Do not hesitate to use the as-needed medications to keep the patient calm and comfortable.
- As long as the patient is calm, comfortable, and clean, remember to rest and take care of yourself.
- This is the time to tell family stories, laugh, cry, light candles, look at photographs, and celebrate this unique and precious life.

Visit the Hospice Care Plan on YouTube for the playlist associated with this section.

Death Care/Grief/Bereavement

GOALS:

- To recognize and know what to do at the time of death.
- To experience the grief that comes with death.
- To find support during bereavement.

WHAT TO KNOW:

- Most people have experienced few deaths; therefore, anxiety is expected and normal.
- Anticipating death starts the grief process.
- Death can often cause profound grief and loss.
- Grief can manifest spiritually, emotionally, and physically.
- The bereavement process varies greatly in its intensity and length.
- Feeling a sense of relief after the death is normal and healthy.
- Each person needs a support system: family, friends, grief groups, counseling. This is especially important if struggling during the bereavement process, which is not uncommon.
- When death is peaceful, family and loved ones can also feel less fear about their own mortality.
- Each state has its own laws regarding after-death procedures.

HOW WILL I KNOW WHEN DEATH HAS ARRIVED?

SIGNS OF DEATH:

- No rise or fall of the chest.
- No feeling of air moving in and out of the nose or mouth.
- No pulse of the heart at the neck or wrist.
- Seeing all facial features smooth out to a calm and peaceful countenance.
- The skin will turn to a soft translucent yellowish hue.
- Trust your instinct, you will know.

WHAT TO DO:

- If possible, contact a mortuary ahead of time and notify hospice of your choice.
- Call your hospice to report the death and the time you discovered or witnessed the death. This will be the recorded time of death.
- You may request a visit from a member of the hospice team.
- The mortuary can assist in writing an obituary and help determine how many death certificates are needed.
- In the interest of everyone's safety, including the community at large, it is imperative to properly waste any remaining medications. Please ask your hospice team about their policy and practice.

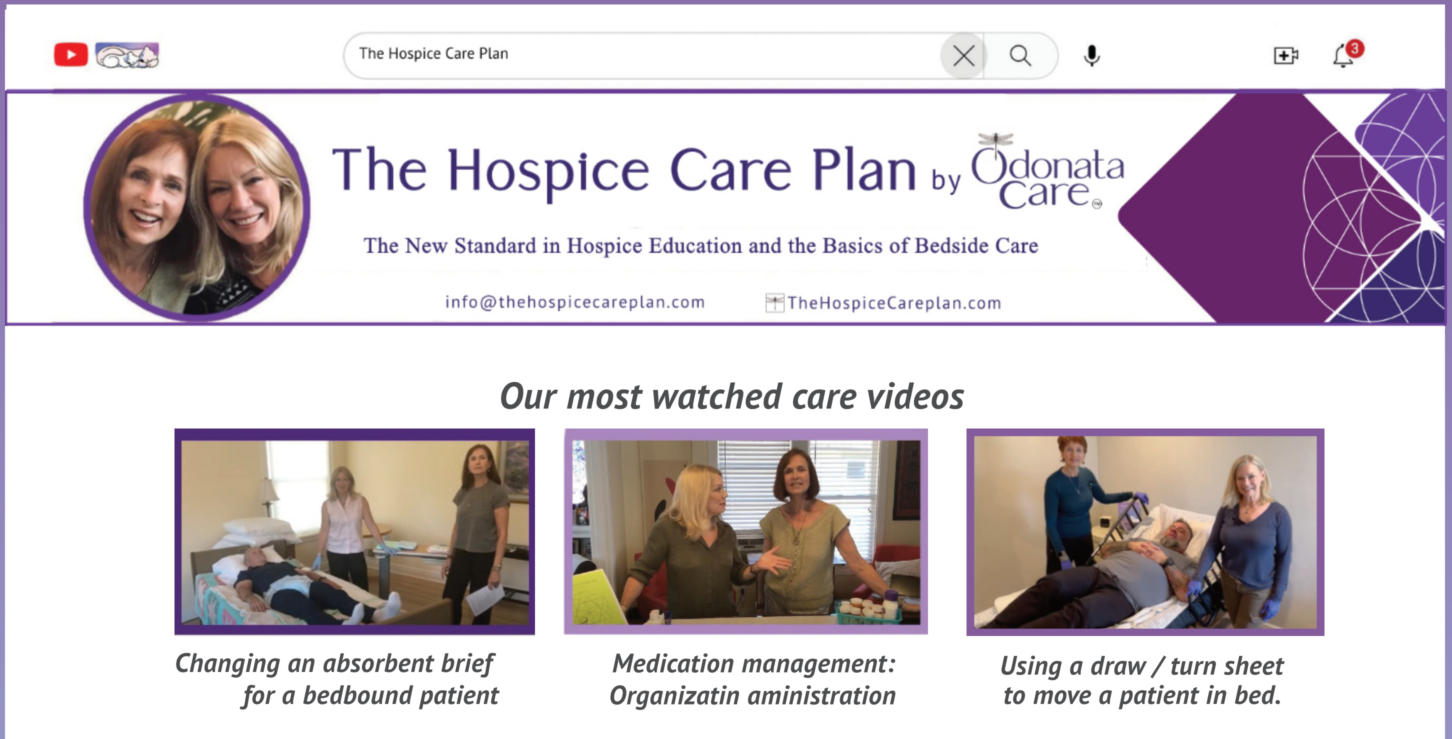
IDEAS AND OPTIONS TO HONOR THIS TIME AND CREATE CLOSURE:

- Take a moment and do what feels right for you and your family. These are suggestions, but not necessary.
- Do not feel rushed. Take as much time as you need to honor their death, your experience, and this life transition.
- Bathe the body and use essential oils, a favorite perfume or fragrance.
- Dress the body, choosing the clothes they would like.
- Light a candle, play music, and set up an altar that honors the loved one.
- Request a visit of the hospice chaplain or your spiritual leader.

GRIEF AND BEREAVEMENT:

- The Hospice Medicare Benefit provides one year of bereavement care following death.
- Each hospice is individual in their supportive care.
- There may be calls, cards, letters, and bereavement group meetings.
- Please don't hesitate to call your hospice when support is needed.
- The role of the hospice social worker is to provide grief counseling and arrange support.
- Most communities have bereavement support groups available.

Videos for Personal Care, Symptom Management and End-of-Life Needs



The Hospice Care Plan

The Hospice Care Plan by Odonata Care

The New Standard in Hospice Education and the Basics of Bedside Care

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Changing an absorbent brief for a bedbound patient

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Using a draw / turn sheet to move a patient in bed.

Introduction	**Medication Management**	**Eating and Drinking**	**Nausea**
Anxiety and Agitation	**Bladder**	**Pain**	**Secretions**
Bowel	**Breathing**	**Personal Care and Safety**	**Transition/Active Dying/Death Care**

Visit the Hospice Care Plan on YouTube for the playlist associated with this section.

“Care is Treatment”

“A Path to Comfort is a practical, compassionate, meticulous, and detailed guide to help families manage the day-to-day care of a loved one in hospice care, from the perspective of two nurses who have provided bedside care to hospice patients for decades. It provides step-by-step directions for such ‘simple’ processes as cleaning or turning a patient, which can often feel overwhelming to family members doing it for the first time. By providing this thoughtful guidance to the caregiver, it can make what sometimes feels impossible—providing superb care to a dying loved one—feel possible, thus boosting the morale of the caregiver and enhancing the care of the person who is ill. It is designed to supplement and synergize with the care offered in the home by a hospice program.”

SUSAN BLOCK, M.D.
Dept. of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute and
Brigham and Women’s Hospital, Professor of Psychiatry and Medicine, Harvard Medical School

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“Hospice nurses, Heyerman and Kizzire, write from years of caring experience. A Path to Comfort is filled with practical wisdom. Down-to-earth and loving, this booklet is a gift to anyone caring for a person who is approaching the end of life.“

IRA BYOCK, M.D.
Founder and Chief Medical Officer Institute for Human Caring at Providence St. Joseph Health,
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As certified hospice and palliative nurses, Brenda Kizzire, RN, BSN, CHPN, and Nancy Heyerman, RN, BSN, CHPN, each have more than two decades supporting hospice patients, families, and caregivers. As passionate and compassionate end-of-life experts, they serve as mentors and educators of nurses, students, hospice volunteers, and the community at large.

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