The Care Plan

A PATH TO COMFORT FOR
THE HOSPICE PATIENT

3rd Edition
Written by two experienced hospice and palliative nurses, this booklet is intended to support hospice patients and families with important information, resources, and tools that guide and educate all involved through a compassionate end-of-life process. It is not designed to replace hospice, but rather to help patients, caregivers, and families speak the same language and literally be on the same page with their hospice experience. At the same time, it provides a quick, easy, hands-on workbook for medication and care management of the hospice patient, offering simple-to-follow instructions and tracking forms to relieve common symptoms that arise during the end of life.

WHAT YOU NEED TO KNOW:

- 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 often live longer and remain more comfortable, with an improved quality of life.

A PICTURE IS WORTH A THOUSAND WORDS: We invite you to visit www.TheCarePlan.net for our helpful online video demonstrations. Each short video will show how to provide personal care in a comfortable, safe manner for both the patient and caregiver. See the full list and descriptions on Page 30.

Throughout the booklet, each available video is denoted with a play symbol: ✔

ABOUT THE AUTHORS

As certified hospice and palliative nurses with over 40 years of hospice experience between us (Brenda and Nancy), our mission is to transform the end-of-life experience through education and support. This booklet was inspired and born out of our long practice at the bedside, with a recognition of the growing need for end-of-life education and support. Our years of extensive education make us experts in our field. We are both passionate, compassionate 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 hospice colleagues as well as for those who are new to the field. It takes an interdisciplinary team to provide the best overall care.

Odonata is the Latin word for “dragonfly,” which represents transformation. We chose this symbol because dying is, at heart, a transformational journey. Experience has taught us that we all find our way to death and we do this in the same way 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.

Brenda Kizzire, RN, BSN, CHPN              Nancy Heyerman, RN, BSN, CHPN
About the Dying Body

Our human body is both a miraculous and mysterious machine. It’s one job is to live and live and live some more. When it’s 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—the blood pressure and pulse—until the last few days of life as it continues to do its everlasting effort—quietly and underneath our awareness. Outwardly there is a natural spiral of decreasing energy, awakeness, and responsiveness. The body asks for and even insists on less food and water, and then shrinks with natural dehydration allowing 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 and 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 body 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 our 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. Considering each case in terms of months, weeks, and days can get us closer to a “best guess” and time frame. 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 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. 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 and your hospice team, the chance of having a compassionate and peaceful death is more attainable.
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.
- Discomfort can rob you of your life energy.
- There can be fear and concern about taking and giving medications.
- 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.

ABOUT MEDICATIONS:
- The comfort medications prescribed are designed to work well together, as long as all interactions have been 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, so start low and go slow.
- It can take trial and error to find the right amount and combination of medications for the most effective symptom management.
- Giving small routine doses of medications avoids the roller coaster of discomfort.

WHAT TO DO:
- Always try non-invasive steps first but 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:
  - 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.

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

MEDICATIONS OFTEN USED FOR COMFORT:
(Actual options may vary between different hospices)
- Opioid medications generally used for pain and/or shortness of breath:
  - MORPHINE
  - OXycodONE
  - METHADONE
  - HYDROCODONE
  - DILAUDID
  - TRAMADOL
- Medications generally used for anxiety or agitation and nausea:
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  - VALIUM (DIAZEPAM)
- The hospice team has 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 8.
## Medication Management

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## Medications/Bowel Movement Tracking

**MEDICATIONS GIVEN:**
Please list any as-needed or PRN medications not on the scheduled daily list

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<th>BOWEL MOVEMENTS</th>
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**PRN / As-Needed Medicines** (Document the use of these medications on page)
**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.
- However, 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.

**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** (this is often harder than it seems):
   - Give time for difficult, scary thoughts or feelings to arise and be spoken.
   - Repeat what you are hearing and ask for clarification: “Tell me more...”
   - Use the opening phrases: “I wish...you weren’t feeling so sad and worried...” “I worry...that you are feeling nervous and stressed...” “I wonder...what we could do to help you feel calmer...”
   - 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.

**WHAT TO KNOW:**
- Anxiety and agitation are normal, expected, and healthy responses to facing end of life.
- However, 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.

**Call hospice if you have done the above and they still aren’t calm and comfort**
**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.
- Losing the ability to manage urination can be distressing, both emotionally and physically.
- Being unable to urinate and not wanting to "wet oneself" 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.

**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.
2. 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. Go to [www.TheCarePlan.net](http://www.TheCarePlan.net) for video demonstration on changing a brief.
4. Are they agitated and restless?
   - When did they last pee? If longer than 12 hours, it may be that they can't.
   - 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. **Catheter care:**
   - 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, you may see blood in the tubing or bag. If urine is flowing, no need to worry, but perhaps encourage increased fluid intake.
   - Leaking around the catheter may occur. If the patient is comfortable, place an absorbent brief on them and notify your hospice team during business hours.
   - Empty the bag when full or at least every day. Measuring is not needed, unless your nurse directs this.
   - Wash the entire genital area and the catheter thoroughly and daily with soap and water or wipes, and after each bowel movement.
   - 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 Bowel Function and Comfort**

**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.
- Disease process and medications also affect the bowels.
- 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:**
- **TMIRALAX** powder in any fluid or food (water, juice - even coffee)
- **SENNA** tablets - a vegetable laxative for softening and stimulation
- **BISACODYL** tablets - for stronger stimulation
- **BISACODYL** Suppository - works directly in the rectum for stimulation and lubrication

Your hospice nurse will give you personalized instructions.

**WHAT TO DO:**
1. Gather needed supplies: gloves, wipes, disposable or washable underpads, absorbent briefs; use pull-up briefs when still active, tabbed briefs when bedbound.
2. Take your prescribed bowel medication to prevent constipation.
3. If no BM by bedtime of day 2, take the next step in the bowel program.
4. If no BM by noon on day 3, call hospice for further instructions.
5. Please always write down the date of every bowel movement and the quality and size, for example: small, medium, large, loose, firm, hard pebbles.

Use the form provided in the booklet or any system that works. This helps the hospice team manage symptoms.

The hospice team will give directions on how to choose and manage the medication(s):
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? No! Neither should your loved one.
- When we can’t breathe, our body’s response is to become anxious.
- Shortness of breath is distressing, can be scary and needs to be addressed.
- Pain and discomfort can cause shortness of breath.
- Medications are the fastest and most effective way to relieve shortness of breath.
- 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. **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 are working too hard.
2. **Stop any activity and rest.**
3. **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.
4. **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 away from the body. This gives the lungs the most space possible.
5. **Directing a fan toward the patient can give relief.**
6. **If a nebulizer is part of the treatment plan, have them use it now.**
7. **Medications:** Follow your hospice nurse’s directions.
   - Make sure the patient is taking their routine medications to prevent 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.**

The hospice team will give directions on how to choose and manage the medication(s):
**GOALS:**
- 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 anything 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.

**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.

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.

6. **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.

7. **STOP IF THERE IS COUGHING, CHOKING, OR THEY TURN THEIR HEAD AWAY.**
   - This is the body’s message, “I don’t want more.”

8. **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 with some mouthwash and a few drops of kitchen oil used with a sponge will help keep the mouth moist.
Nausea, Vomiting, and Queasiness

**Goals:**
- Rapid and sustained relief from nausea (sick to one’s stomach).
- To enjoy eating and drinking favorite foods and drinks.

**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 one of the most common causes 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, refer to 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, Coca-Cola, or ginger or mint tea.
   - Hold off on eating until the nausea has passed.
   - Refer to the bowel program.

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 used by hospice may be administered rectally to avoid 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 of whatever patient desires.
   - If nausea or vomiting returns: Stop drinking anything more and consider repeating 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**

The hospice team will give directions on how to choose and manage the medication(s):

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**Visit www.TheCarePlan.net for online video demonstration**
## 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.
- 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.

### 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.
- Be creative: use pillows, props, music, massage, distractions. Note what works.
- Consider medications if the patient is not comfortable after 5–10 minutes.

### 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.
- Write down the as-needed medications used on the medication form.
- Your hospice team will need this information to adjust the schedule.
- 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.

### 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.

### 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.
Secretions and Gurgling in the Active Dying Process

**GOALS:**
- To support and educate the family and caregivers during the active dying process when the sounds of breathing change.

**WHAT TO KNOW:**
- The sounds of breathing can be distressing for families.
- 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 patient usually doesn’t experience any discomfort at this time.
- 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.

**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. See www.TheCarePlan.net for video demonstration.

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 out every 2–3 hours and before giving medications. Start with the lips, roll into the mouth, and swab along the outside of the teeth.
   - 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.
   - If they allow, enter inside the teeth to clean 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.
   - Flatten the top of the bed and raise the foot of the hospital bed.
   - Turn the patient onto their side, almost to the tummy. Let gravity help. The fluids will run out of the mouth.
   - 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.

**WAR AND SKIN CARE INSTRUCTION**

- Provide containment and comfort for any breakdown of the skin that does occur.
- Consider this a substitute for brushing the teeth.
- Liberally apply lip balm.
- Use a humidified room.

**MEDICATION:**
- If you have followed all of the steps above and secretions remain a problem, your hospice nurse may start a medication.
- It will slow the mouth from producing saliva but will not dry secretions already there.

**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 not active 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 sitting still in one position—lack of blood flow causes the skin to break down.
- In dying process, skin will change (sometimes drastically), including color, moisture and temperature.

**WHAT TO DO:**
- Assess for red spots, scrapes, bruises, dryness, rash, and odors and notify your hospice nurse if you identify any of these problems.
- Care for their skin as you would yours—keep it clean and dry.
- Use their favorite products: oils, lotions, fragrances.
- Change the position every 2–3 hours while waking hours and at least once during the night to prevent skin breakdown from pressure. Even heavy blankets on the toes can cause skin breakdown.
- At least 3 pillows or props (rolled up blankets or towels) are needed to provide comfortable positioning.
- 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.

**WOUND AND SKIN CARE INSTRUCTION**

- Assess for red spots, scrapes, bruises, dryness, rash, and odors and notify your hospice nurse if you identify any of these problems.
- Care for their skin as you would yours—keep it clean and dry.
- Use their favorite products: oils, lotions, fragrances.
- Change the position every 2–3 hours while waking hours and at least once during the night to prevent skin breakdown from pressure. Even heavy blankets on the toes can cause skin breakdown.
- At least 3 pillows or props (rolled up blankets or towels) are needed to provide comfortable positioning.
- 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.

Visit www.TheCarePlan.net for online video demonstration.
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 patient 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 dangerous time for potential 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.
- Visitors can be helpful but can also add emotional stress and fatigue to both the patient and family.
- Bedrails are often used for safety and to assist movement in bed; the purpose is not for restraint.

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.
- The hospice team can be the “bad guy” in helping to set clear, comfortable visitation boundaries to preserve everyone’s energy. Now is not the time to host, but to allow others to care for you!
- It’s OK and encouraged to ask family, friends, and volunteers to help with chores and errands on a scheduled and recurring basis.
- 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 out of sight if possible.
- Obtain personal care supplies before needed, if not provided by hospice: gloves, wipe, 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 bed is flat, sheets are 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 PICTURE IS WORTH A THOUSAND WORDS:
We invite you to visit www.TheCarePlan.net for our helpful online video demonstrations. Each short video will show how to provide personal care in a comfortable, safe manner for both the patient and caregiver. Throughout the booklet, each available video is denoted with a play symbol.

Index to Personal Care and Safety Videos

Our video tutorials have been created to assist families and caregivers to quickly learn care giving techniques for the bed bound patient.

Please go to TheCarePlan.net for our entire playlist of care videos.

1. Placing a Turn or Draw Sheet under a Patient: Rolling a patient side to side to place a flat sheet under the patient which can then be used to move and turn the patient without handling the body.

2. Positioning for Comfort: To Lie on the Back: How to position a patient comfortably on their back using a turn or draw sheet and pillows.

3. Positioning for Comfort: To Lie on the Side: How to position a patient comfortably on their side using a turn or draw sheet and pillows or props.

4. Moving a Patient up in Bed with a One-person Assist: Using a draw or turn sheet, which is already under the patient, to pull or move the patient toward the head of the bed.

5. Moving a Patient up in Bed with a Two-person Assist: Using a draw or turn sheet, which is already under the patient, to pull or move patient up in bed.

6. Changing an Absorbent Brief for a Bed Bound Patient: Careful review of removing a soiled brief, cleaning the patient, and applying a clean absorbent brief.

7. Bathing a Bedbound Patient: Instruction for giving a bed bath to a person confined to bed.

8. Transfer of a Patient from Bed into a Wheelchair: Siting the patient on the side of the bed and then lifting and transferring into a wheelchair.

9. Positioning to Lying from a Sitting Position at the Edge of the Bed: Moving a patient from an upright sitting position into a comfortable lying position.

10. Oral Care, Secretions, Hydration and Nutrition for the Hospice Patient: This video reviews tips on eating and drinking for the hospice patient. It demonstrates how to provide oral care to keep the mouth fresh and to assist in preventing swallowing problems.

11. Medication Management: Organization and Administration: This video describes how to organize both scheduled and as needed medications for clarity and accuracy.
Transition into Dying

GOALS:
- To recognize and understand the signs of transitioning into the dying process.
- To keep patient comfortable, calm, and safe during this period.

WHAT TO KNOW:
- 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.
- There will be ups and downs from day to day and even hour to hour.
- Because patients are losing their normal mental and physical abilities during this time, they are more at risk for falls and injuries.
- Due to the decline in ability, there is an increased loss of personal control that can be distressing and anxiety producing.
- A person’s life bubble shrinks and loses its energy, mentally and physically. They start detaching from life around them. Do not take it personally when you feel them pulling away; this subtle shift is normal and necessary.
- Pets are not only cherished family members, but often have the most intimate connection to the dying person.
- It is not uncommon to notice changes in the pet’s behavior as the patient is transitioning.
- The need to communicate diminishes at the same time the swallow and voice weakens.
- Learning into what the transitioning body wants and doesn’t want, is easier on the patient and escorts a smooth active dying process.
- Go with the flow.
- This is not always a steady state of decline, as stated above. This can be confusing and unsettling.

WHAT TO DO:
- Patients should no longer be left alone at this time.
- Arrange for increased caregiving needs. The hospice social worker can help with this.
- Allow for increased sleep.
- Honor what patients want and don’t want to eat and drink. Nutrition is no longer important. It is very hard for families and caregivers to accept this, but it offers a sense of control for patients.
- Assess for safe swallowing and adjust foods and fluids as needed. See Eating and Drinking.
- Treat incontinence in a ‘matter of fact’ manner and have products available. See Bowels and Bladder.

SIGNS OF TRANSITION:
- Increased sleeping is to be expected.
- Appetite will decrease, with less interest associated for food and fluids, along with difficulty swallowing.
- Mental changes: forgetful, less engaged in TV, reading, and conversations.
- This is often a time of increased life review.
- Anxiety may bring restless and irritability.
- Agitation may present itself with reaching, unsettled behaviors, wanting to sit or lie still.
- Transition is often the start of incontinence and decreased output of bowel and bladder.
- Increased weakness: unable to get in and out of bed or chair and unable to walk independently.
- Skin changes with dry, flaking, red spots (pressure sores) due to less activity.
- Changes in breathing patterns and depth may be noticed.

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 and all its organs are slowing down and shutting down their functions.
- 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 feel anticipation and even relief as death approaches. This is healthy, anticipatory grief.
- A calm, peaceful space helps to promote a comfortable death, and sets the stage for acceptance and healthy bereavement.

WHAT TO DO:
- Continue the turning schedule of every 2–3 hours during waking hours and once or twice during the night.
- 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.
- 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.
- As long as the patient is calm, clean and comfortable, 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.

SIGNS OF ACTIVELY DYING:
- Patients are fully bedbound and generally are no longer waking up.
- Eating and drinking has ceased and they are losing their ability to swallow.
- No longer can they take their routine medication, 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 irregular.
- Skin may become pale, gray, cool, and clammy and appear mottled or bluish.
- As dehydration deepens, the body appears to shrink and the bones become more prominent.

WHAT TO KNOW:
- The active dying process generally lasts 1–3 days, but this can vary.
- The body and all its organs are slowing down and shutting down their functions.
- This time can be physically and emotionally intense for patients, families, and caregivers.
- Acceptance and healthy bereavement.

WHAT TO DO:
- The active dying process generally lasts 1–3 days, but this can vary.
- The body and all its organs are slowing down and shutting down their functions.
- This time can be physically and emotionally intense for patients, families, and caregivers.
- Acceptance and healthy bereavement.
Careful review of removing a tourniquet showcases our mission of transforming the aging and end of life experience through education and support. This video describes how to remove a tourniquet.

**Instruction for giving a bed bath to a person confined to bed.**

1. **Positioning for Comfort:**
   - Placing a turn or draw sheet under a patient:
   - 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 or a favorite perfume.
   - 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.

2. **Positioning for Comfort:**
   - Positioning to lying from a sitting position at the edge of the bed:
   - Rolling a patient side to side to place a flat sheet under the patient, which is already under the patient, to pull or move up in bed.

3. **Positioning for Comfort:**
   - Bathing a bedbound patient:
   - Using a draw or turn sheet, moving a patient from an upright sitting position into a comfortable lying position.

4. **Positioning for Comfort:**
   - Changing an absorbent brief for a bedbound patient:
   - Soiled brief, cleaning the patient, and applying a clean absorbent brief.

5. **Positioning for Comfort:**
   - To lie on the back: How to position a patient comfortably on their back using a turn or draw sheet and pillows or props.

6. **Positioning for Comfort:**
   - To lie on the side: How to position a patient comfortably on their side using a turn or draw sheet and pillows or props.

7. **Positioning for Comfort:**
   - Bathing a bedbound patient: Instruction for giving a bed bath to a person confined to bed.

8. **Positioning for Comfort:**
   - Transfer of a patient from bed into a wheelchair: Sitting the patient on the side of the bed and then lifting and transferring into a wheelchair.

9. **Positioning for Comfort:**
   - Positioning to lying from a sitting position at the edge of the bed:
   - Moving a patient up in bed with a two-person assist: Using a draw or turn sheet, which is already under the patient, to pull or move the patient toward the head of the bed.

10. **Positioning for Comfort:**
    - Moving a patient up in bed with a one-person assist: Using a draw or turn sheet, which is already under the patient, to pull or move the patient toward the head of the bed.

11. **Positioning for Comfort:**
    - Oral Care, Secretions, Hydration and Nutrition for the hospice patient: This video reviews tips on eating and drinking for the hospice patient. It demonstrates how to provide oral care to keep the mouth fresh and to assist in preventing swallowing problems.

12. **Positioning for Comfort:**
    - Medication Management: Organization and Administration: This video describes how to organize both scheduled and as needed medications for clarity and accuracy.

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**DISCLAIMER**

The information contained in this written reading 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, excluding 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.
“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

“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.”

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