


The Care Plan

A PATH TO COMFORT FOR
THE HOSPICE PATIENT



Odonata
Care

3rd Edition

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Introduction

WHAT IS THE PURPOSE OF THIS GUIDE?

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 a hospice team, people are able to die comfortably wherever they live.
- ◆ The goals of care shift from cure and rehabilitation to quality of life and comfort.
- ◆ People who receive good symptom management often live longer, 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 accompanied by a play button icon.

ABOUT THE AUTHORS

As certified hospice and palliative nurses, over 40 years of experience between us (Brenda and Nancy), our mission is to transform the end-of-life process through education and support. This booklet was inspired and born out of our long practice at the bedside and 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 excellent end-of-life care.

Odonata is the Latin word for "dragonfly" and 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 rebirth in the same way we live. We hold deep compassion and respect for the patient at the 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, 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, awakened 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 the patient to endure this transition. Without fluid we die within approximately 4 - 14 days based on the amount of fluid that they start with. The body wants to be quiet and calories are no longer important or needed. We all store energy in the form of calories in our fat and muscles to keep the balance of energy needed while dying. The kidneys filter out and excrete all of the important elements in the blood. The breath slows and changes, increasing the amount of oxygen that 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, the body conserves 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 predicting how much time a person has left to live. Considering each case in terms of months, weeks, and days is closer to a "best guess" and time frame. What we know is that when someone is declining monthly, they likely have months left to live. The same is true for both weeks and days and even down to hours. You can see them becoming weaker, eating less, being less active over the period of a week and you can see them have months to live. If the decline has become more rapid and now the changes are occurring daily, 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 will live, but this booklet can assist in estimating where the person is on their life continuum. Hopefully this information will help you see more clearly which end-of-life stage the patient is experiencing. Knowing this information can help reduce anxiety and the ability to stay focused in the present moment, while planning for life going forward and you.

In the final weeks of life, patients generally need 24-hour care, because they can no longer care for themselves. Often the vigil during this time is the hardest overt work for the care circle. The waiting game can be both a trial and a blessing. Family members can reminisce and reconnect over the loved one's sleeping form or work together providing mutual support. There is no rush...we only die once, and everyone finds their own individual way.

SYMPTOM MANAGEMENT

Proper symptom management is essential to facilitate the most compassionate and peaceful end-of-life process. This booklet shows the remaining energy to be spent on 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.

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 #: _____

CAREGIVER AGENCY: _____ PHONE #: _____

CAREGIVER: _____ PHONE #: _____

CAREGIVER: _____ PHONE #: _____

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.
- ◆ 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 the

ABOUT MEDICATIONS:

- ◆ The comfort medications prescribed are designed to work well together, as long as interactions have been reviewed for safety.
- ◆ There are many routes to administer medications: oral, sublingual (under the tongue), rectal, and injectable.
- ◆ These medicines are simple to use and will only be used if needed.
- ◆ Everyone responds differently to medications, so start low and go slow.
- ◆ It can be a trial and error to find the right amount and combination of medications for the most effective symptom management.
- ◆ A small room temperature refrigerator avoids the need for a cooler to transport medications.

COMMON MEDICATIONS OFTEN USED FOR COMFORT:

(Actual numbers 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:
 - 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.

SEE Forms for Routine and As-Needed Medication Use on Page 8.

Medication Management

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.

See Medication Forms, starting on the next page.

MAKE A SAFE SPACE TO MANAGE AND ORGANIZE MEDICATIONS

- ◆ Clear an area that is large enough for all the medications and is easily accessible, near the patient.
- ◆ Consider using a towel or large sheet of paper to provide a flat 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 if the hospice nurse can refill, usually once a week. This will help with running out of medications.
- ◆ Safety is very important. Keep out of reach of children and pets.
- ◆ A lock box may be needed for a caregiver with dementia or other caregivers who has access to the medications.

HOW TO USE LIQUID MEDICATIONS

- Hospice uses medications when the cancer is so advanced that 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. You do not need to go under the tongue.
- Because the medication is placed in the mouth, there is no need to worry about swallowing.
- Moisten and hold the oral sponges before giving liquid medications.

HOW TO USE BOTH PILL AND LIQUID TOGETHER:

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

Visit www.TheCarePlan.net to view videos for medication management.

Medication Management

| SCHEDULED MEDICINES | | | TIME | | | | PURPOSE |
|---|----------|------|---------|---------|---------|---------|-----------------|
| Name | Strength | Dose | AM Hour | Mid-day | PM Hour | Bedtime | What is it for? |
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| PRN Medicines (Document the use of these medications on page 7) | | | | | | | |
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Medications/Bowel Movement Tracking

| MEDICATIONS GIVEN: Please list any as-needed or PRN medications not on the scheduled daily list | | | BOWEL MOVEMENT | |
|--|-------------|-------|----------------|----------------|
| Date & Time | Medications | Given | Date & Time | Amount/Quality |
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Pain and Discomfort

Individualized Instructions for Pain and Discomfort Relief

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 standard.
- ♦ The patient may say they are in pain yet show outward signs.
- ♦ A patient can look fully comfortable when moved or touched. But as care is provided, they can demonstrate pain, resist care, and become combative.
- ♦ Expect patients to change position when remaining in one position for too long.
- ♦ When the patient is not comfortable, 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. If you don't see what has been described, visit www.TheCarePlan.net
- ♦ Reposition for comfort. Go to www.TheCarePlan.net for video demonstration.
- ♦ Be creative: use pillows, blankets, massage, music, or other distractions. Note what works.
- ♦ Consider medications if the patient is not comfortable after 5–10 minutes.

MEDICATIONS FOR PAIN AND COMFORT:

- ♦ Use long-acting medications as prescribed by your hospice team.
- ♦ Use short-acting (as-needed) medications to provide relief when the pain breaks through.
- ♦ List down the as-needed medications used on the medication administration form.
- ♦ The 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.

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.

The hospice team will give directions on how to choose and manage the medication(s). There are many other options if these medications are not effective.

NSC
 ♦ Restless, agitated, and irritable OR completely shut down.

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 and become more personally when you feel the subtle shift is normal and necessary.
- ◆ Pets are not only cherished family members but often have the most intimate connection with the dying person.
- ◆ It is not uncommon to see changes in the pet's behavior as the pet is the one who senses the subtle shift.
- ◆ The need to complete tasks at the same time the swallow and speak weakens.
- ◆ Transition into what the transitioning body wants and doesn't want, is essential to the patient and the caregiver during the active dying process.
- ◆ Not all patients go through a steady state of decline, as noted above. It can be confusing and unsettling.

WHAT TO DO:

- ◆ Patients need increased caregiving during transition. Visit www.TheCarePlan.net for personal care and safety videos.
- ◆ Patients should no longer be alone at this time.
- ◆ Arrange for increased caregiving needs. See hospice social worker for assistance.
- ◆ Allow for increased sleep.
- ◆ Honor what patients want and need to eat and drink. Nutrition is no longer a priority and is very hard for families and caregivers to accept this, but it is a sense of control for patients.
- ◆ Assess for need for allowing for fluids and foods as needed. Eat and Drink.
- ◆ Incontinence is a "matter of fact" manner and products available. See Bowels and Bladder.

SIGNS OF TRANSITION:

- ◆ Increased sleeping is to be expected.
- ◆ Appetite will decrease, with less interest and desire for food and fluids, along with difficulty swallowing.
- ◆ Mental changes: forgetful, possible confusion, less engaged in TV, reading, and conversations.
- ◆ 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 decreased output of both 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 losing 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.
- ◆ Dehydration is an expected and normal part of dying. The use of IV fluids may not be comfortable during the dying process. The patient may be dry and quiet.
- ◆ Expect breathing changes. This can cause anxiety in those caring for the patient. This is natural and expected.
- ◆ Skin temperature can change drastically. Change in the color of the skin. Changes for temperature can be massive and reflective at this point.

SIGNS OF ACTIVELY DYING:

- ◆ Patients are fully bedbound and generally are no longer waking up.
- ◆ Eating and drinking has ceased. They are losing their ability to swallow.
- ◆ No longer can they take routine medication but only the concentrated.
- ◆ They are incontinent of both bowels and bladder. Frequency of both have dramatically increased.
- ◆ Turning themselves in bed is no longer possible and they rely on others to keep them clean, comfortable and safe.
- ◆ Changes in breathing rhythm and breathing are apparent, with irregular and slack jaw. Breathing patterns are irregular and there are often long pauses between breaths up to 45 seconds.
- ◆ Oxygen levels will decline, generally without any signs of discomfort.
- ◆ 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 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.



Video Index and More Information

Our website, thecareplan.net, showcases our mission of transforming the aging and end of life experience through education and support. When fully utilized this booklet improves the standard of hospice care. Please visit the website to better understand the far-reaching benefits of this essential booklet when used throughout the hospice experience.

A PICTURE IS WORTH A THOUSAND WORDS:

We invite you to visit www.TheCarePlan.net for our helpful online video demonstrations. Each video shows 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: 

- 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 proper positioning.
- 4. Moving a Patient up in Bed with a One-person Assist:** Using a turn or draw sheet, which is already under the patient, to pull or move the patient up to the head of the bed. 3. 4.
- 5. Moving a Patient up in Bed with a Two-person Assist:** Using a draw sheet, which is already under the patient, to pull or move the patient up to the head of the bed.
- 6. Changing an Absorbent Brief for a Bedbound Patient:** Caregiver review of removing a soiled brief, cleaning the patient, and applying a clean absorbent brief.
- 7. Bathing a Bedbound Patient:** Instructions for giving a bath to a person confined to bed.
- 8. Transfer of a Patient from Bed into a Wheelchair:** Sitting the patient on the side of the bed and then transferring the patient into a wheelchair.
- 9. Positioning to Lying on a Wheelchair at the Edge of the Bed:** Moving a patient from an upright sitting position to a comfortable lying position.
- 10. Oral Care, Secretions, and Nutrition for the hospice patient:** This video reviews creating and caring for the hospice patient. It demonstrates how to provide oral care to keep the mouth fresh and assist in preventing swallowing problems.
- 11. Medication Management: Organization and Administration:** This video describes how to organize and administer scheduled and as needed medications for clarity and accuracy.

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, 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.**

"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."

IRA BYOCK, M.D.

Founder and Chief Medical Officer Institute for Human Caring at Providence St. Joseph Health, Author of *Dying Well* and *The Best Care Possible*
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