

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, doula, 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 on-line 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, awakens, 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 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.



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, doula, 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.





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 by Odonata Care
The new standard in Hospice Education and the Basics of Bedside Care
info@thehospicecareplan.com TheHospiceCareplan.com

Our most watched care videos

- Changing an absorbent brief for a bedbound patient
- Medication management: Organization administration
- 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

“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



“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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ABOUT THE AUTHORS

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.



Transformational End of Life Education and Support

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The Hospice Care Plan on YouTube



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