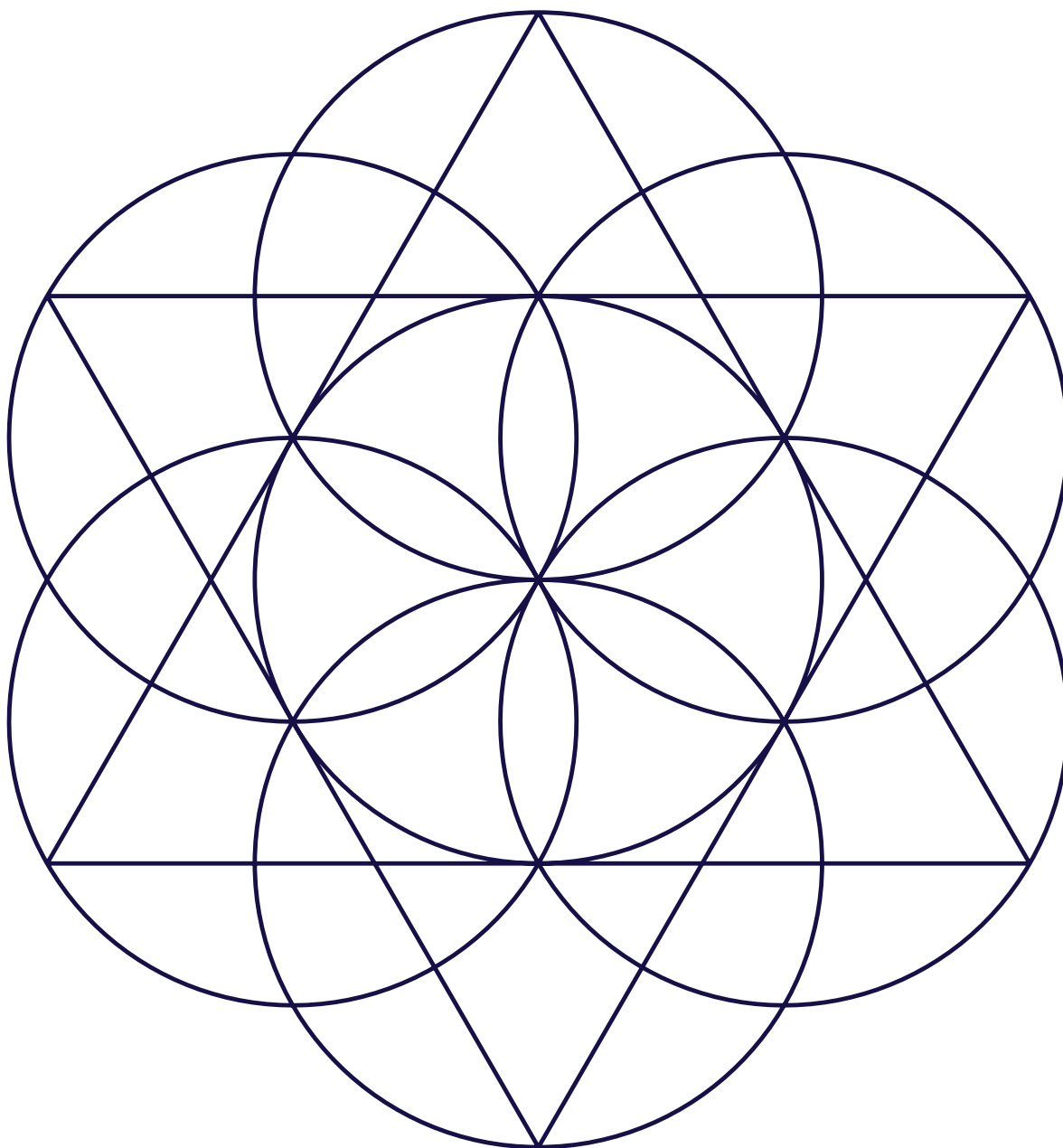


A PATH TO COMFORT

———— CARING FOR THE HOSPICE PATIENT ————



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INTRODUCTION

GOAL: TO LIVE THE BEST WE CAN, UNTIL WE DIE!
TO PROVIDE A QUICK AND EASY, HANDS-ON GUIDE FOR CARE AND SYMPTOM MANAGEMENT
OF THE HOSPICE PATIENT.

WHAT TO KNOW:

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

PURPOSE - WHY THIS BOOKLET?

- To provide simple to follow instructions regarding care needs and for relieving common symptoms that arise during the end of life.
- This booklet 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.
- It offers a learning tool for caregivers, nurses and providers not familiar with end of life care.

BOOKLET CONTAINS:

- A *CENTRAL SOURCE OF INFORMATION* for patients, families, caregivers and the hospice team
- A *COVER PAGE* providing all *CONTACT* information *AT A GLANCE*
- Room for personal and *INDIVIDUALIZED INSTRUCTIONS* from your hospice team
- *LINKS* to *SHORT VIDEOS* demonstrating how to provide care hospice patients
- Forms to organize and document medication use.

HOW TO USE: -

- On admission to hospice, begin filling out the contact list on page 3 with your hospice team.
- As a problem arises, turn to the page of the symptom that is presenting itself.
- Follow the instructions from the booklet and your detailed instruction from your hospice team.
- Throughout the booklet, the symbol ♥ indicates a YouTube video demonstrating care and safety instructions. Go directly to YouTube and search: OdonataCare, or see last page for the video index.
- The medication section includes valuable and much needed organizational tips and tools.
- We suggest you put a “sticky note” on the medication page and any page of symptoms being experienced.

ABOUT DYING: No matter our background, cultural orientation or spiritual beliefs, we can all agree that birth and death are the transition into and out of life. As we grow our energy and life expands, so also, as we move towards death, our life bubble starts to shrink and we begin to detach from the world around us. Our bodies literally begin to shrink and the space we take in our homes and life becomes smaller. And bit by bit we detach from our life. The veil between reality as we know it and the mystery of the final transition thins. This marks the end of a life – some bad, some good – but it is ours.

MEDICATION MANAGEMENT

GOAL: 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 nurse may use this term.

ABOUT MEDICATIONS:

- All of the comfort medications prescribed work well together and can safely be given together to achieve comfort.
- There are many routes to administer medications: oral, sublingual (under the tongue), rectal, injectable.
- These medicines are simply tools in the toolbox and will only be used if needed.
- Everyone responds differently to medications so, start low, 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 rollercoaster of discomfort.

MEDICATIONS OFTEN USED FOR COMFORT: (Hospices vary)

- ### 1. Opioid medications generally used for PAIN and/or SHORTNESS OF BREATH

MORPHINE OXYCODONE METHADONE HYDROCODONE DILAUDID TRAMADOL

- ## 2. Medications generally used for ANXIETY or AGITATION and NAUSEA

LORAZEPAM (ATIVAN) HALOPERIDOL (HALDOL) VALIUM (DIAZEPAM)

- The HOSPICE NURSE is an EXPERT in using these medications.
- Being open to the suggestions, will likely ACHIEVE COMFORT MORE QUICKLY.

[illegible]

WHAT TO DO:

1. ALWAYS TRY non-invasive steps first, but do not wait too long.
2. Take ROUTINELY SCHEDULED medications CONSISTENTLY.
3. USE the as needed or PRN medications for breakthrough symptoms not managed by your routinely scheduled medicines.
4. KEEP TRACK of the as needed or PRN medications.
 - Write it 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 medications regimen.
 - Request medication refills at least 48 hours prior to needing more.

[illegible]

5. MAKE A SAFE SPACE TO MANAGE AND ORGANIZE THE 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.

6. 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. Does not need to go under the tongue.
- Because they are concentrated, don't worry about swallowing.
- Moisten and clean the mouth with the oral sponges before giving liquid medications.

7. 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.

SYMPTOM MANAGMENT

ANXIETY AND AGITATION

GOAL: TO RECOGNIZE AND MANAGE THE SIGNS OF EMOTIONAL AND PHYSICAL ANXIETY AND AGITATION
TO ENJOY ADEQUATE AND CONSISTENT SLEEP

WHAT TO KNOW:

- Anxiety and agitation are normal, expected and healthy responses to facing end of life.
- Anxiety can be very subtle and difficult to recognize.
- Anxiety can be worse than pain and is sometimes not well managed.
- Pain and anxiety often feed off each other and may need to be treated simultaneously.
- Loss of mental ability with forgetfulness and periods of confusion and even hallucinations are normal and expected but can be distressing for patients and families.

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

SIGNS OF AGITATION:

- Can't sit still, restless, pacing or 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 AND 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.

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...."
- We often will never know what is causing 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 likely time to give the medications

Instructed by your hospice nurse. 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.

[illegible]

CALL HOSPICE IF YOU HAVE DONE THE ABOVE AND THEY STILL AREN'T CALM AND COMFORTABLE

MEDICATION / Bowel movement tracking form[illegible]

BRIEF CHANGES: AT LEAST DAILY AND AFTER EACH SOILING OF URINE OR STOOL

This is a COMPLEX PROCESS, BUT IT IS DOABLE. Please watch the video: ♥

1.
 - Check the brief every 2-3 hours (during repositioning is a good time to do this).
 - Assure the room is private, warm, and comfortable.
 - Gather supplies and assure they are within reach: clean brief, wipes or basin of warm water with washcloth and soap, gloves, trash can at bedside, and disposable bed pad if needed. If the draw sheet is soiled and also needs to be changed, have a clean one within reach.
 - Tell the patient what you plan to do.
 - Flatten the bed.
2.
 - Release the tabs on the brief or tear at the seams.
 - Lift the front of the brief away from the body and roll it down and into itself.
This helps contain the soiled brief.
 - Tuck the rolled brief down between the legs.
 - Wash the front of the groin area with soap and water or wipes getting into the creases.
3.
 - Using the turn sheet, turn the patient onto their side.
 - As you pull the loosened brief off the hip, again roll it down and inside itself.
 - Tuck the rolled brief under the lower hip.
 - Thoroughly clean the buttocks and rectal area with the wipes or soap and water.
 - If there has been loose stool, lift the top leg so all creases can be cleaned.
 - It helps to have a second person assisting to lift and support the leg when possible.
 - This is a time to ask for help.
- 4 .
 - Open the clean brief and place the tabbed end toward the head of the bed at the waistline.
 - Roll the farthest side of the brief halfway to the center.
 - Tuck the rolled side under the patient's back and buttocks with the upper edge at the waistline (next to the soiled old brief).
5.
 - Changing the draw sheet at the same time as the brief requires an extra step.
 - Lay the draw sheet over the patient from shoulders to hips.
 - Place the open clean brief on the center of the draw sheet.
 - Reach across to the far side and roll the turn sheet to the center which will incorporate the clean brief in the roll.
 - Place and tuck the rolled edge under all, so that the clean brief is at the waist line.

6.

- Roll the patient fully to the opposite side of the body.
- They will be rolling over both the old and new brief and turn sheets.
- Remove and discard the soiled brief and old draw sheet.
- Complete any washing necessary.
- Now unroll the clean brief (and draw sheet if being changed) making sure it is well centered.

7.

- This is the time to assess the skin for any signs of irritation or breakdown.
- If there is open skin or a bedsore, use a hairdryer on low for 3 - 5 minutes to fully dry the area, bringing heat to encourage faster healing. And it feels great!
- Apply skin lotion or ointment to protect the skin as needed.
- This is a good time to massage reddened or sore areas. It promotes increased circulation, prevents breakdown, and again, provides comfort and feels great.

8.

- Now roll the patient onto their back.
- Pull the brief up between the legs and attach both tabs to the stomach for a snug - not tight, fit.
- Check that the elastic is comfortably tucked in the groin creases.
- If there is any sign of skin inflammation or breakdown, inform your hospice nurse for further instructions.

TRANSITION INTO DYING

GOAL: TO RECOGNIZE AND UNDERSTAND THE SIGNS OF TRANSITIONING INTO THE DYING PROCESS AND TO KEEP PATIENTS COMFORTABLE, CALM AND SAFE DURING THIS PERIOD.

WHAT TO KNOW:

- Transition usually lasts 4-14 days, but this can vary widely and the patient can even float in and out of full alertness to even active dying during this time. Because the swings can be so acute and broad, be patient with yourself and the patient.
- 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, mentally and physically, is shrinking and losing its energy.
- They start detaching from life around them. Do not take this personally when you feel them pulling away. This subtle shift is normal and necessary.
- The need to communicate diminishes at the same time the swallow and voice weakens.
- Leaning into what the transitioning body wants and doesn't want, is easier on the patient and escorts in 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.

SIGNS OF TRANSITION:

- Increased sleeping is to be expected.
- Decreased appetite with less interest and desire for food and fluids, along with difficulty swallowing.
- Mental changes: forgetful, less engaged in TV, reading, and conversations and possible confusion.
- 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.
- 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.

WHAT TO DO:

- [illegible]

ABOUT THE AUTHORS:

We, Brenda and Nancy, hold over 40 years of hospice experience between us and are both Certified Hospice and Palliative Nurses. We are passionate nurses who serve as mentors and educators of nurses, students, hospice volunteers and the community at large regarding care at the end of life. This booklet was inspired and born out of our hospice experience as nurses at the bedside and the recognition of the growing need for end of life education and support. Odonata is the Latin word for dragonfly, which represents transformation. We chose the dragonfly because dying is transformational. 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 the end of life and for those who provide love and care for them. We hope this booklet and videos help ease your way on this path.

OUR MISSION:

To transform the end of life experience through education and support

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We would like to honor and thank all of the patients, families, caregivers and professional colleagues who have contributed to our growth as nurses and women.

We dedicate this project to our children who have taught us humility, patience, and love. We thank them for their continual enthusiastic support and love.

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INDEX TO YOUTUBE VIDEOS:

Please go to YouTube and type in Odonata Care and the title of the desired video, or type in this URL address, which will take you to our entire playlist of care videos.

♥ <http://bit.ly/3goeFep>

1. PLACING A TURN OR DRAW SHEET UNDER A PATIENT: ♥ <https://youtu.be/X66XE2FzNgw>
2. MOVING A PATIENT UP IN BED WITH A TWO PERSON ASSIST: ♥ https://youtu.be/YAX_zmNuwuc
3. MOVING A PATIENT UP IN BED WITH A ONE PERSON ASSIST: ♥ https://youtu.be/sCT5vM1H_4A
4. POSITIONING FOR COMFORT: TO LIE ON THE BACK: ♥ <https://youtu.be/QkcauWW9L6o>
5. POSITIONING FOR COMFORT: TO LIE ON THE SIDE: ♥ https://youtu.be/6M5_eTPUWpo
6. TRANSFER A PATIENT FROM BED INTO A WHEELCHAIR: ♥ <https://www.youtube.com/watch?v=NtvmImVSq8E&t=6s>
7. POSITION TO LYING FROM SITTING AT THE EDGE OF THE BED: ♥ <https://youtu.be/N1kW0EiENEc>
8. CHANGING AN ABSORBENT BRIEF FOR A BED BOUND PATIENT ♥ <https://youtu.be/4Js4atWSJu0>
9. ORAL CARE, SECRETIONS, HYDRATION, AND NUTRITION ♥ <https://youtu.be/1EdRuThEFAQ>
10. MEDICATION MANAGEMENT: ORGANIZATION AND ADMINISTRATION ♥ <https://youtu.be/uKzDG6LLNNM>

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, the author, makes no representation and assumes 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.**

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"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 "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 MD

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, MD

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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