Module 6 – Honoring Wishes for Comfort

Narrative for Individual Reading

All staff who work with the medically fragile or chronically ill have the opportunity to promote dignity and maximize quality at the end of life. The POLST conversation includes discussion of comfort measures; providing palliative care and comfort measures is an integral component of POLST.

How do we improve quality of life for the patient/resident with chronic, life-limiting illness that we cannot cure?

How do we assist the individual and their family with understanding progressive illness or frailty?

Most people have little or no experience with chronic illness and dying. Palliative care is the art and science of relieving pain, suffering and symptoms associated with a serious disease. Palliative care treats the whole person, aiming to meet the physical, emotional and spiritual needs of the resident and family.

How do we assist the individual and their family with transitioning from aggressive, curative medical treatments, to focusing on maximizing quality of life through excellent symptom management?

How do we help the individual and their family know what to expect during the dying process and reassure them that we will be with them through this last stage of life?

It is vital to tell the resident and family that you will:

- be there for them and continue to provide care.
- provide medicine to relieve pain, shortness of breath, anxiety and any other distressing symptoms.
- listen to them and help provide emotional and or spiritual support during illness, transition and loss.
- help family members provide support to the individual and each other.

Each of us touches our patients/residents who are in the final chapter of their life. Our caring and compassion, our listening, our touch makes a difference for the patients/residents and their families.
**Transitioning to Palliative Care:** the following story illustrates a patient choosing to receive comfort measures only.

**A Patient Perspective**

I talked to my doctor last week and told him that I didn’t want to go back to the hospital for treatment anymore. He asked me why and I told him this:

“I’m more comfortable here and the staff knows me and knows what I need. The people at the hospital are nice and they want to help, but they don’t know my needs as well. At the hospital, I get stuck with a lot of needles and tubes and get wheeled from test to test. I suppose that they want to help me, but I’m not sure that all of the tests and treatments really help me that much. I guess they help me live a little longer; but to me it doesn’t seem to be worth the pain and discomfort that goes along with being in the hospital.”

My doctor told me that he understands and supports my decision. He told me that he would leave instructions for the staff here at the nursing home so that they would also understand. We changed my POLST (Section B: Limited Additional Interventions, Do not transfer to hospital for medical interventions) and my doctor assured me that they would continue to take care of my needs and take care of new problems, like bronchitis or a bladder infection. But he said that they would consider my comfort first. He also told me that if they couldn’t keep me comfortable here, with the medicines and equipment at the nursing home, then I would have to go to the hospital.

Some of my family had a difficult time with my decision. I think they have a hard time thinking of having to let go. But I know that they will understand when they really consider what is best for me.

Even I sometimes have doubts – that’s probably natural isn’t it? But I sleep better at night since I have made this decision. I also know that I can always talk with my doctor about how I am feeling.

*****
The patient/resident and or surrogate decisionmaker may choose to transition to palliative care with comfort measures at the recommendation of the physician due to declining health from disease progression. Current medical treatments may be more burdensome than beneficial. Additional medical treatments may not be tolerated due to weakened hearts, kidneys or other body systems.

**Models of End-of-Life Care** include Hospice and Palliative Care. Definitions of palliative and hospice care include:

“**Palliative care** is the comprehensive management of physical, social, spiritual, and existential needs of patients, in particular those with incurable, progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and the family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs, and practices.”


“**Hospice programs** provide palliative care to terminally ill patients and supportive services to their families and significant others... in both home and facility-based settings. Physical, social, spiritual, and emotional care is provided during the last stages of illness, during the dying process, and during bereavement by a medically directed interdisciplinary team consisting of patients/families, professionals, and volunteers.”


Providing Comfort Measures as requested by a resident’s POLST encompasses the components of hospice and palliative care. A key premise of POLST is that everyone will receive symptom management to promote comfort. This document will focus on palliative care, although a resident and/or family may choose to have hospice care.

Embracing the philosophy of palliative care to maximize quality of life with pain and symptom control, including psychological and spiritual support is fulfilling the goal of choosing POLST Comfort Measures. Palliative care does not mean stopping active medical interventions and treatment. The following graph shows the value of providing palliative care throughout the spectrum of chronic illness.
Progressive life-limiting diseases such as cancer, congestive heart failure, COPD, diabetes, and Alzheimer’s, often lead to declining health and symptoms that benefit from palliative care. On-going aggressive treatment may not be effective or the treatment may not be tolerated by the patient or resident. Multiple emergency department or hospital admissions may signify increased frailty or progressive illness.
Relief of distressing symptoms and pain management can improve comfort and quality of life. Symptom management includes evaluation and treatment of any distressing or uncomfortable symptoms such as dyspnea (shortness of breath), fatigue, nausea, depression, anxiety, constipation or loss of ability to do basic activities of daily living.

When goals of care are focused on enhancing quality of life, comfort and dignity can be promoted by:

- Modifying diet choices to meet the resident’s wishes, while promoting caloric intake if feasible and desired by the resident.
- Allowing food and fluid volume to be determined by the resident.
- Expecting weight loss.
- Providing active pain management, focusing on routine medications, **not** relying on PRN schedules.
- Attempting to reduce risk for skin breakdown.
- Anticipating dysphagia (difficulty swallowing) and when present, discontinuing oral medications.
- Encouraging family visitation and communication.
- Reviewing and/or revising POLST.

**A Pain Assessment Tool** promotes comprehensive pain management, including physical, psychological and spiritual pain assessment:

- Complete a careful assessment. Performing an assessment provides the foundation for effective control of pain.
- Ask open-ended questions, and listen carefully to what the patient says.
- Use developmentally appropriate pain assessment scales to determine the site, intensity, and quality of pain.
- Assess for psychological and spiritual pain caused by emotional, social and spiritual factors (e.g. anxiety, depression, loneliness, loss of meaning, financial concerns).
- Assess for pain related to medication side effects, constipation, urinary retention, etc.
- Reassess at regular intervals, after initiation of each new treatment, after each new report of pain or change in quality/intensity of pain, and at appropriate intervals after interventions.
- Treat pain empirically while investigating its etiology.

*Pocket Guide to Hospice/Palliative Medicine*: American Academy of Hospice and Palliative Medicine, 2003
Pain Management:

- The goal is prevention of pain.
- Use continuous or long-acting medication for chronic pain to provide steady pain relief.
- Use short-acting medication for breakthrough pain. Medical orders for “prn” medication for breakthrough pain are important to have available if pain escalates and the resident is uncomfortable.
- Do not rely on prn medications for control of on-going or persistent pain.
- Oral or sublingual medications are preferred.
- Avoid IM pain medications; IM injections are painful.
- Unmanageable pain may require intravenous or subcutaneous treatment and/or hospitalization.
- Discuss change in treatment plan with physician if poor pain control.
- Monitor and treat for side effects of pain medications.
- Treat to avoid constipation.

Symptom Management:

A patient/resident’s care may be focused on palliative, comfort measures for a few days or for months. Care is directed at promoting comfort and symptom management, with each day “the best day possible” for the individual. When disease progresses or a significant decline occurs and death is approaching, the focus and intensity of comfort measures increases.

It is important to have rapid access to medications which may be required in the last days or hours of life. When a resident requires secretion management, it is beneficial to have the prn medical orders and medicines available. Not all pharmacies stock the medications which may be required during the last days or hours of life.

Obtain prn orders for pain, dyspnea (shortness of breath), anxiety and secretions. See attached sample Comfort Measures Orders template.
Family Education on Normal Process of Dying:

Many patients and families have little or no experience with dying. Patients and families often want to talk, but may be afraid to ask questions or share their feelings. It is important to:

- Ask open-ended questions and listen.
- Provide information, respond to questions, and be available.
- Tell them every death is different.
  - Sometimes the final days are “more challenging”, but we will treat any symptoms.
- We do not know the exact timeframe of death.
  - Knowledge that death is close is often difficult to predict. For example, if someone is not responding, no longer taking food or fluids, their time to death “may be very fast or may be a week, or possibly a little longer.”
  - Tell the patient and family, “We will be there for you”.
  - An important point for everyone to remember, including staff, is the purpose of comfort measures is neither to hasten death, nor to prolong life artificially, but to support patient and family through symptom management and communication.

Clinical signs that the body is physically “shutting down” include:

- Decreased hunger and thirst are normal and occur with almost everyone before death.
  - If caregivers express concern about “starving to death”, remind them that forcing food or drinks may actually cause discomfort as the body cannot swallow and may choke, and the body is “shutting down” and cannot metabolize and use the food.
- Patient is given permission to refuse food or fluids (and will be more comfortable without food or fluids in the stomach).
- Loss of appetite is normal.
  - Intravenous fluids and artificial feedings do not improve comfort and often cause fluid retention in the lungs and swelling in the body, again because the body is shutting down.
- Clenching of teeth may be the only way for the patient to express his/her desires.
- The patient will have increased weakness, fatigue and inability to get out of bed.
  - Moving in bed may be uncomfortable.
  - Pain medication is often needed before gentle turning or repositioning.
- The patient tends to sleep longer and longer periods of the day.
  - When awake, the patient may speak very little, or look confused, and may not recognize family and friends.
  - Encourage families to continue to speak softly, as the patient may still hear and feel the close presence of others, even if he or she cannot talk or respond.
  - Encourage families to continue to express their love and caring for the patient.
- Breathing will change and often becomes irregular.
  - Breathing may become very shallow.
- Gasping breaths and periods of time without breathing may occur.
  - Irregular breathing, a sign of neurologic progression closer to death, includes Cheyne-Stokes respirations (irregular breathing with periods of apnea).
  - Family education is important; this type of breathing is expected and is not associated with discomfort or the sensation of “suffocating.”
  - Oxygen may not be beneficial, although some patients and families find it comforting.
  - Opioids or the benzodiazepines are helpful to manage shortness of breath.
- Rattling or gurgling may occur, from loss of ability to swallow and cough.
  - As the body shuts down and ability to swallow food and fluids are lost, the ability to cough and gag are also lost.
  - Fluids collect in the back of the throat and in the lungs, causing noisy breathing, crackling and gurgling (sometimes called the “death rattle”).
  - Suctioning is generally not beneficial and can cause significant discomfort. Most secretions are too deep to suction.
  - Dyspnea or discomfort can be treated with opioids to reduce sensation of shortness of breath and/or benzodiazepines to reduce anxiety and dyspnea.
  - Large amounts of secretions can be minimized with either atropine drops, glycopyrrolate or scopolamine patch (see comfort measures handout or sample orders).
- Arms and legs may become cool to touch and color may be more “dusky” or mottled.
  - Giving intravenous fluids at this time will not change the shutdown of circulation that occurs.
  - Additional fluids usually increase the amount of edema, swelling and fluid overload in the lungs.
- Loss of control of bladder and bowel may occur.
- Urine output will decrease and may stop.
- Body temperature may become colder or warmer than usual.
  - Treat fever prn with acetaminophen and fewer blankets.
  - Families may ask if antibiotics should be used to treat fever; treatment decisions should consider if antibiotics will meet the patient’s goals or just prolong the dying process.
- Hearing is often present even when the patient appears unconscious.
  - Encourage family to speak and touch patients even if they are unconscious.

**Emotional and spiritual “letting go” includes:**
- Increased confusion about time, place and identity of familiar people.
- Seeing things that others don’t see, including deceased loved ones (and is reported as a welcoming and pleasant experience for the dying).
- Restlessness, attempting to climb out of bed, “I have to go somewhere.”
  - Teach families to respond to mild restlessness in a calm, quiet way, with gentle reassurance, turning, or soft music.
  - Consider if pain or other symptoms are causing restlessness and try to treat.
- Talking to people who are not there.
  - Maintain a peaceful environment and calm presence.
- Ask patient and family about feelings and concerns regarding death and dying.
- Ask if they have any specific rituals or cultural beliefs and traditions regarding death and dying that need to be completed.
  - Offer assistance to call clergy, etc.
- Involve family in personal care. Encourage family to participate in personal care, such as feeding (if desired and tolerated by patient), mouth care, and gentle massage.
- Encourage family to bring pictures from home.
- Cover patient with special blanket or blanket from home.
- Remove limits on visiting hours.
End-of-Life Vital Signs:

- “Routine vital signs” are usually discontinued when death is near and focus is on comfort measures only.
  - Machinery to assess routine vital signs may cause patient or family distress.
  - Information from routine vital signs, like respiratory rate and oxygen saturation, are usually not helpful and may cause confusion about treatments.

- “End-of-life vital signs” help assess comfort.
  - Heart rate (apical pulse with stethoscope or palpated radial pulse) to evaluate if tachycardia, often a sign of discomfort in the unconscious patient).
  - Respirations, looking at quality and character, such as irregular or apneic spells which show approaching death.
    - Note: Opioids should not be held for slow-shallow respirations in the dying patient.
  - Secretions, wet respirations (gurgling, rattling, crackling) caused by pooling of oral secretions, can be treated.
  - Peripheral perfusion, inspecting/palpating extremities to evaluate mottling and cooling, which are signs that death is near.
  - Temperature, sweating and fever are common at the end of life and can be treated with acetaminophen, removal of blankets, fan, etc.

Key Points to “Honor Wishes for Comfort:”

- Relief of distressing symptoms and pain can improve comfort and quality of life.
- Medications are often required to relieve symptoms in the last days or hours of life.
- Medications are to reduce pain and suffering, not to hasten death.
- The patient is dying from the medical illness, not the medications.
- Educating and supporting families can reduce suffering and distress during their loved one’s death and afterwards.

We can honor wishes for comfort.
Pain Assessment and Management Overview

A Pain Assessment Tool promotes comprehensive pain management, including physical, psychological and spiritual pain assessment:

- Complete a careful assessment. Performing an assessment provides the foundation for effective control of pain.
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- Discuss change in treatment plan with physician if poor pain control.
- Monitor and treat for side effects of pain medications.
- Treat to avoid constipation.
Comfort Care Measures Overview

**Vital signs** – prn to evaluate “End-of-Life Vital Signs” for comfort, heart rate (tachycardia), respiration (apnea, rapid rate/tachypnea), temperature if warm to touch, secretions (gurgling or coarse crackles).

**Diet** – Patient choice of time, quantity and type of food as tolerated. Family may provide food.

**Activity** – as tolerated. Position of comfort.

**Oxygen** – 2 to 3 L/minute/nasal cannula prn shortness of breath (dyspnea).

**Pain:**
Optimal pain management is best achieved with routine or long-acting medication, such as Morphine, Dilaudid, Oxycontin, Duragesic, etc. with a routine dosage schedule.

Breakthrough pain, identified by verbalization, moaning, restlessness, grimacing, etc, is treated with a short-acting oral medication, such as Roxanol or Dilaudid liquid prn for breakthrough pain, shortness of breath, restlessness, agitation, cough. Note: many residents are unable to ask for prn medications; observe for signs of discomfort.

**Anxiety, dyspnea, agitation or restlessness** – Ativan Intensol 2 mg/ml – small dose sublingual or oral, prn agitation, anxiety, shortness of breath (may be beneficial on a regular basis for symptoms or to augment pain control).

**Secretions** – Scopolamine patch 1.5 mg – apply one to two patches q 72 hours prn secretions, and/or Glycopyrrolate 1 mg po TID prn secretions, and/or Atropine 1% ophthalmic 1 to 2 drops SL q 6 hours prn secretions.

**Constipation** (prevention is key) – DSS 100mg or 250mg 1 to 2 BID Plus Senna 1 to 2 po BID, or Sorbitol 30 ml po daily or BID prn constipation. If severe, Lactulose 15 to 30 ml BID to TID.

**Nausea** – PRN orders for compazine or phenergan. Ativan prn helps nausea.

**Agitation with psychosis, delirium** – Haldol sublingual (SL) prn hallucination, confusion, severe restlessness.
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- Educating and supporting families can reduce suffering and distress during their loved one’s death and afterwards.

We can honor wishes for comfort.
SNF Comfort Measures Orders

Date _______ Time _______ Resident ___________________________
All orders must be dated, timed and signed by MD. All boxed items must be checked to be ordered. Boxes left unchecked will not be activated.

☐ No CPR, No Intubation; Discontinue any prior orders for resuscitation
☐ No Transfer to Hospital

**Pain Assessment** every 2 hours and prn (signs of pain include RR >20, dyspnea, restlessness, agitation or grimacing)

Diet: ☐ per comfort needs ☐ NPO ☐ Other: _____________ ☐ Unlimited Family Visitation

Vital Signs: ☐ discontinue ☐ prn ☐ every shift

Weights: ☐ Discontinue

Discontinue the following:
- Routine Labs/Xrays
- Fingerstick Glucose Testing
- Respiratory Therapy treatments prn
- Discontinue Respiratory Therapy treatments
- Discontinue all previous medications except the following medications

☐ Continue the following medications: __________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________

☐ Hold all po medications if unable to swallow
☐ Oxygen ___ Liter/minute per cannula prn comfort

**Pain and Dyspnea Medication:**
- ☐ Roxanol 20 mg/ml
- ☐ Hydromorphone 2 mg/ml

Oral:
- Give ___ml sublingual or po every ___ hour ☐ while awake or ☐ around the clock
- Give ___ml sublingual or po every 2 hour prn breakthrough pain or dyspnea

Or: _______________________________________________________________________

Transdermal:
- ☐ Fentanyl patch ___ mcg/hour topical. Change every 72 hours.

**Anxiety:**
- Oral: ☐ Ativan Intensol 2 mg/ml: give ___ml sublingual every ___ hour prn anxiety, dyspnea, N/V

**Nausea/Vomiting:**
- ☐ Ativan Intensol 2 mg/ml: give ___ml sublingual every ___ hour prn N/V
- ☐ Prochlorperazine (Compazine) 25 mg suppository q 4 hour prn N/V
- Other: _________________________________________________

**Constipation:**
- ☐ Bisacodyl (Dulcolax) Suppository 10 mg daily prn constipation
- ☐ Sorbitol 30 ml po BID prn constipation
- ☐ Lactulose 30 ml po BID prn constipation

**Secretion Control:**
- ☐ Scopolamine patch 1.5 mg disc topical every 72 hours prn secretions
- ☐ Glycopyrrolate 1 mg po TID prn secretions
- ☐ Atropine 1% ophthalmic solution: give 2 drops sublingual every 3 hour prn congestion

☐ Acetaminophen 650 mg po or rectal suppository every 4 hours prn temp > 100 (Do not exceed 4 gm in 24 hours)

Verbal Order/Telephone Order from Dr. ___________________________ Date: _____ Time: _____

Verification of Telephone Order by: ___________________________ Date: _____ Time: _____

Physician Signature: ___________________________ Date: _____ Time: _____

Orders Transcribed by RN/LVN: ___________________________ Date: _____ Time: _____
Skilled Nursing Facility Comfort Measures Program

Policy Statement

Our facility, in an effort to provide respectful and compassionate care to our residents, has adopted the following Comfort Measures Program. This program will provide support to the resident and their family, with special focus on relief of pain and distressing symptoms. Resident and family support, with consideration of their social and cultural needs, shall be emphasized.

Policy Interpretation and Implementation

Chronically ill residents in a state of declining health shall be considered for inclusion in the Comfort Measures Program. Transition to Comfort Measures shall be contingent upon the agreement of the resident or their surrogate decisionmaker, the resident’s attending physician and the Intra-Disciplinary Team (IDT).

The Comfort Measures Program will emphasize quality of life and comfort issues. Care Plans shall be revised after consideration of disease progression, and evaluation of the efficacy and burden of treatment options. Discontinuation of current treatments may result, if they are determined to be more burdensome than beneficial. Any new treatment added to the resident’s care plan should be with the primary purpose of improving comfort. The Care Plan will include the unique needs of the resident and family. Physician orders will be revised to reflect the focus of comfort measures and the individual needs identified in the care plan.

Residents in the Comfort Measures Program will be re-evaluated for current medical status, quality of life, and pain and symptom management needs as their condition changes and at least quarterly.
# STAGES OF DYING

Dying is a sacred time of life – a time with meaning and important life tasks

<table>
<thead>
<tr>
<th>Early Stage</th>
<th>Mid Stage</th>
<th>Early Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What You See</strong></td>
<td><strong>What is Happening</strong></td>
<td><strong>What You Can Do To Help</strong></td>
</tr>
<tr>
<td>➢ A decrease in both eating and drinking which may last from days to weeks.</td>
<td>➢ The Body naturally begins to conserve energy and requires less nourishment.</td>
<td>➢ Moisten the patient’s mouth with toothettes &amp; swabs frequently.</td>
</tr>
<tr>
<td>➢ Less interest in food. Eating may become more of a burden than pleasure.</td>
<td>➢ There is no “hunger” and no “suffering” with this process.</td>
<td>➢ Offer sips of fluid or chips of ice.</td>
</tr>
<tr>
<td>➢ Occasional choking on fluids.</td>
<td>➢ IV Fluids and artificial feeding will <em>NOT</em> promote comfort or prevent death.</td>
<td>➢ Offer bits of food if desired.</td>
</tr>
<tr>
<td>➢ Feeling “full” quickly.</td>
<td></td>
<td>➢ Follow the patient’s wishes about taking food and fluids.</td>
</tr>
</tbody>
</table>

**Early Stage**

Changes in physical appearance may last a few hours or days.

- Often the patient’s hands and feet may feel cool and may darken in color.

**Mid Stage**

- Patient will respond less and less to you and his/her surroundings.
- Eventually the patient is completely unable to speak or move.
- This usually happens during the last few days of life.

**Early Stage**

Patient is preparing for release and detaching from surroundings and relationships.

- This is a physical and spiritual response to the dying process.

**Mid Stage**

- Assume that the patient can hear everything.
- Say your name and speak softly.
- Touch gently and frequently.
- Do not ask questions which require answers.
- You may find prayers or meditation helpful at this time.

Adapted from Queen of the Valley Medical Center, Napa Valley Hospice and Adult Day Services
## STAGES OF DYING
Dying is a sacred time of life – a time with meaning and important life tasks

<table>
<thead>
<tr>
<th>Last Stage</th>
<th>Late Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What You See</strong></td>
<td><strong>What is Happening</strong></td>
</tr>
<tr>
<td>Intermittent disorientation and restlessness may occur in most patients.</td>
<td>This is due partly to the changes occurring in the patient’s metabolism.</td>
</tr>
<tr>
<td>You will notice a gradual decrease in the patient’s urine output. If the patient has a urinary catheter, the urine may appear very dark. The bowel movements may stop altogether or the patient may become incontinent during the last few days.</td>
<td>As the circulation decreases, kidneys and bowel function may be reduced. Muscles may relax causing incontinence for the patient.</td>
</tr>
<tr>
<td>Breathing becomes more irregular. Breathing may be shallow and have long pauses, which become more frequent and longer in duration as death approaches, especially during the last few days. Increasing sounds of congestion in the chest and a rattle in the throat may be heard during the last hours</td>
<td>Circulation of internal organs will decrease especially the heart and lungs. Throat muscles will begin to relax and the lungs will lose their ability to clear fluids.</td>
</tr>
<tr>
<td>Signs of Death: No breathing No heartbeat No reaction to verbal commands or touch Jaw relaxed and mouth slightly open</td>
<td>What Happens after Death: Call hospice or home health staff Do not call 911 – staff will notify doctor and mortuary</td>
</tr>
</tbody>
</table>

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