How to Advocate for a Patient Who's Having "End-of-Life" Challenges

Quiz Button

Course Objectives:

1. Identify how to care for constipation.
2. Explore how to treat itchy skin conditions.
3. Learn about caring for wounds.
4. List potential questions that might arise when supporting someone with their end-of-life decisions.
5. Understand the use of life support.
6. Identify the issues surrounding the use of breathing or feeding tubes.
7. Discuss the use of sedation at the end of a patient's life.
8. Indicate the issues that arise when hospitalization happens.
9. Identify situations most at risk for communication breakdown.
10. Understand how to use validation therapy and rapport with people who are confused or withdrawn.

The purpose of this course is to help you think clearly and holistically about how you can best support people who are experiencing a variety of common "end-of-life" challenges.

Constipation

Constipation is not fun to have or to treat. The goal in treating constipation is generally not to “cure” something, but to help the person return to the best possible balance that will allow a normal bowel movement to be passed. The four main components that produce a normal BM are: solid waste, water, motility and lubrication.

Solid Waste – Either too much or too little is a problem. The intestine is most efficient pushing an intermediate volume of solid waste. People on low-fiber diets may improve if fiber is added, BUT when people are consuming minimal fluids or who have weak gut peristalsis (e.g. most dying people), then extra fiber can worsen the constipation.

Water Content – Water content in stool depends on

- How much water the person drinks (this is often decreased in sick people)
- Whether the person takes a diuretic med that make them excrete more water
- How much water is absorbed from and secreted into the intestine
- How fast stool moves through the bowels (peristalsis)
- Any of these variables can be manipulated. Medical prescribers often suggest giving hyperosmolar particles that draw and hold water, e.g.
    - Magnesium salts, like in milk of magnesia
    - Non-absorbable sugars, like in sorbitol and lactulose
    - Polyethylene glycol [PEG]
        - Note: Magnesium and phosphorus salts make renal failure worse
        - Hyperosmolar solutions may worsen dehydration by drawing body water into the gut and out of circulation in the blood

        - Sickly-sweet sorbitol and lactulose may be difficult to for persons to tolerate… PEG is flavorless and may be better tolerated

Motility (Lack of peristalsis) – Persons with low-activity levels (for instance: people who sit or lie most of the time) and people who use certain drugs (see below) will have bowel motility problems. Senna preparations, which stimulate the bowel, are generally effective for this. Use senna tablets (or granules, liquid, or tea), starting with 1 tablet at bedtime. That can be gradually increased up to 4 tabs twice a day (total 8 per day) if needed. Note: Before you start giving senna, be sure to give an enema to remove any hardened stool 'plug' or the person might experience serious cramping as the increased peristalsis tries to move the hardened plug.

- **Medications that can cause or worsen constipation:** Opioids, anticholinergics (e.g., tricyclic antidepressants, scopolamine, oxybutynin, promethazine, diphenhydramine), lithium, verapamil, bismuth, iron, aluminum and calcium

Lubrication simply softens the stool and makes it more slippery. This helps minimize pain that can make a person hold back. The most commonly used lubricant is an over-the-counter product named dioctyl sodium sulfosuccinate (DSS, or docusate), which decreases stool surface tension much like soap. Usual dosage is 240 mg once or twice daily. DSS also tastes like soap, so liquid DSS should never be given by mouth, but it may be given through a tube.

- Note: DSS is commonly used in combination with senna when a person is taking opioid pain meds, but it's generally inadequate as the only approach
- Mineral oil is another lubricant that can be used as an

enema, but it should not be given by mouth because pneumonitis can result if the person aspirates a little
- Glycerin suppositories can provide lubrication and draw-in water due to their hyperosmolar particles

Vitamin C: Vitamin C is a natural and very effective approach to reducing constipation, which I’ve seen work time and again but I’ve never heard a physician recommend. Vitamin C comes in tablets and powders, and the powders make it easy to mix in water or juice if tablets are hard for the person to swallow. Start with 1000 mg twice a day and increase until a bowel movement happens. Then adjust the dose slightly down or up until the right bowel movements occur. There’s no chance of overdose because what cannot be used by the body will be excreted in the urine. Meanwhile, the person will receive the side benefits of vitamin C’s antioxidative properties.

Itching Skin

Itching (pruritus) is a common and often distressing symptom near the end of life. A variety of factors can cause itching in dying people, and they’re grouped here in categories:

- Dermatological (dryness, wetness, irritation, eczema, psoriasis)
- Metabolic (hepatic failure, renal failure, hypothyroidism)
- Hematologic (iron deficiency, polycythemia, thrombocytosis, leukemia, lymphoma)
- Drugs (opioids, aspirin, drug reactions)
- Infectious (scabies, lice, candida)
- Allergy (urticaria, contact dermatitis, drug reactions)
- Psychogenic (fear, anxiety, nervousness)

Management of itching involves first eliminating the cause when possible, then secondarily relieving the symptoms. Symptom-relieving strategies include:

- **Moisturizers**: The mainstay of treatment is skin hydration. Note: Most over-the-counter preparations only have small amounts of moisturizer—they are mostly water. Serious dryness requires oils and goos (such as petroleum jelly) that people find oily or greasy. It helps to apply them after bathing, over damp skin, with a superficial covering.
- **Cooling agents** (e.g. Calamine and/or Menthol in aqueous cream, 0.5%-2%) are mildly antipruritic. They can act as a counterirritant or anesthetic.
- **Antihistamines** can be helpful in relieving some itches, for instance itch caused by taking morphine. The physician can also prescribe other meds for this if you think morphine is the cause.
- **Topical steroids** may be helpful if there's also inflammation. These are best applied in ointments rather than creams because the ointments are more beneficial for dryness.
- **Soaking in an oatmeal bath** is an old-fashioned but effective remedy. You can buy a product called 'Aveeno' at the drugstore or you can make your own by blending about 3/4 to 1 cup of plain, unflavored quick-cooking oatmeal into a fine powder and putting it into a sock, a coffee filter bag, or a bundle made from a handkerchief and floating it in the bath water.

Wounds

Few things can worsen a person's quality of life more than an oozing, odorous, painful, and bleeding wound. Foul-smelling non-healing wounds are common in bodies nearing the end-of-life, whether they are caused by pressure ulcers, vascular disease, or malignant tumors. Strong wound odors can lead to social and physical isolation, altered body image and self-worth, and can also frighten and challenge caregivers.

Malignant wounds often have dying tissue in them, which is why there’s an unmistakable offensive odor. The choice of dressing is generally the same as for pressure ulcers. However, malignant wounds raise additional issues that deserve comment.

Note: It’s recommended that you seek professional help from a wound care expert when you’re dealing with draining wounds.

Drainage can happen in surprisingly large amounts from malignant wounds. The overall goals are to:

- Protect the healthy skin around the wound from the effects of this moisture
- Protect the person’s dignity
- Prevent others from contacting infectious drainage

Bleeding is common in malignant wounds because the surface of a malignancy may be fragile. Bleeding can be small and oozing or it can become profuse. Any dressing that comes into contact with the surface of a wound needs to be non-stick so it doesn’t tear the surface when it’s pulled off. If the wound is painful, you can request the physician to order local anesthetics.

Dressings serve both infection control and cosmetic goals. A good option is to use a foam dressing that absorbs the drainage and minimizes the frequency of dressing changes. Typically a thick gauze pad is also placed on top of the foam dressing.

Alginate dressings are made from sterilized seaweed. They’re especially good for wounds that have drainage. They’re one of my favorites because they can stay in place as long as they’re still adhering to the body, and are easy to remove when they start to come loose. You can buy these at the larger drug stores and on the Internet.

Malignant wounds carry a high risk of superficial infection, especially with anaerobic or fungal pathogens. Odor is frequently the first sign of an anaerobic infection, along with a beige, yellow or green drainage. If the infection is only superficial, then topical treatment with metronidazole or silver sulfadiazine ointments may be sufficient. However, if there's evidence of deeper infection, then oral meds should be used too.

Yogurt or buttermilk, applied for 15 minutes after a wound is cleaned, then rinsed off, has been reported to control malignant wound odor, though studies are limited. These are thought to control bacterial proliferation by lowering a wound's pH. Also honey is bactericidal and has been increasingly studied for wound healing. There's some evidence that it decreases odor.

If the wound is determined to be non-healing, then topical agents like povidone (a form of iodine) can be used, however some people find povidone irritating and painful. Povidone is cytotoxic to bacteria and will help keep the wound clean, but it should not be used for wounds that are expected to heal because it's damaging to normal granulation (healing) tissue. One approach is to dilute it to half-strength and see if that's enough to kill the bacteria. If so, it will be much gentler to the body's tissues.

Managing odor can be assisted by using odor absorbers, e.g., kitty litter or charcoal briquettes placed on a cookie tray underneath or near the bed. Remember to change it regularly. In addition, there are charcoal dressings that can be used to cover particularly bad smelling wounds. Additional approaches include putting a burning flame (such as a candle) in the room in an attempt to combust the odor. One can also introduce a competing aroma, such as vinegar, vanilla, or coffee. There are also several natural citrus odor neutralizers on the market that can be helpful. Fragrances and perfumes should be avoided.

Handling Healthcare Issues That May Arise

If you’re supporting someone who’s making end-of-life choices, here are some more common care questions that may come up.

- Should life support be used?
- What if the patient’s heart stops beating?
- What if breathing or feeding tubes are suggested?
- Should the patient be sedated?
- Should antibiotics be used?
- What if the patient has a pacemaker?
- Does the medical staff know the patient’s wishes?
- Will refusing treatment cause the family legal trouble?
- What if a health care provider disagrees with family members?
- What if a health care provider is unfamiliar with the family’s views about dying?

Should Life Support Be Used?

The healthcare provider may ask if machines can be used to keep the patient’s vital organs working, such as a machine to help with breathing (ventilator) or to help failing kidneys remove wastes from the blood (dialysis). Such “life support” was designed to be a temporary measure that allows the body to heal itself so it can work normally again. Life support is not intended for indefinite use for someone’s body that’s at the end of its life cycle.

The situations in which life support would or would not be used should be clearly stated in a written document, like a living will, that records a person’s end-of-life care wishes in case he or she is no longer able to speak for him or herself. Discussing your wishes about life support with a trusted family member or other person could prepare this person – called a health care proxy – to speak for you if necessary. You may wish to formalize this relationship with your health care proxy by using a legal document known as a health care power of attorney. This will help ensure that your wishes for life-support use at the end of life are respected. State laws indicate who can serve as a health care proxy.

What If the Patient’s Heart Stops Beating?

A stopped heart can sometimes be restarted by cardiopulmonary resuscitation (CPR) or with a machine that provides electric shocks (defibrillator). CPR is most effective on people who were generally healthy before their heart stopped.

Often, CPR does not succeed, especially in an ill person who’s already frail. The force required for CPR can also cause serious new medical problems (broken ribs or collapsed lung) and result in a more traumatic death.

If the patient does not want to be resuscitated, a copy of a signed Do Not Resuscitate (DNR) order containing that information needs to be provided to the health care provider overseeing care. The patient’s health care proxy should also have a copy, and family and friends should know the patient’s wishes.

DNR orders do not stop all treatment. They only mean CPR will not be used. These orders are not permanent – they can be changed if the situation changes. DNR forms vary by state and are usually available on the Internet. Check with your state’s Department of Health for a DNR form.

What If Breathing or Feeding Tubes Are Suggested?

Sometimes a healthcare provider suggests technologies to assist with breathing or eating, such as a ventilator or a feeding tube.

Physicians often feel like they have to suggest these technologies to prevent themselves from the possibility of a lawsuit based on not doing everything possible to save a person’s life. But their suggestions do not mean they’d do them if it was their loved one. A good rule of thumb is to ask the provider what they’d do if they were in your shoes.

A ventilator requires intubation, which means a tube is inserted down the throat into the windpipe. If the ventilator is required for more than a few days, the healthcare provider may suggest a tracheotomy instead, which means the tube is inserted directly into the trachea through a small cut in the throat. This bedside surgery can carry risks, including collapsed lung, bleeding, and a plugged tube.

Feeding tubes, which may be suggested when a patient cannot or will not eat, are inserted one of two ways: through the nose (a nasogastric or NG tube) or directly into the stomach through an opening in the side or abdomen (a gastric or G tube, sometimes called a PEG tube, shorthand for percutaneous endoscopic gastrostomy). Feeding tubes carry risks for infection, pneumonia, and nausea. For someone who’s dying, a feeding tube may cause many more discomforts than not eating. Not eating (fasting) is actually an important part of the natural dying process. This is covered in detail in Steps 1 and 5.

Because feeding and breathing tubes can be quite uncomfortable, people who have them are often sedated or restrained to prevent them from pulling out the tubes.

Should the Patient Be Sedated?

Sometimes near the end of life, a health care provider may suggest sedation to manage symptoms that are not responding to treatment and that make the patient uncomfortable. This means using a medicine that puts the dying person in a sleep-like state. Sedation does not cause a person to die more quickly if given as prescribed, and it can be stopped at any time. Comfort care medicines for symptoms like pain may still be used while someone is sedated. A person who’s sedated may still be able to hear, so talking with them may be comforting even though they do not respond. Sedation may also interfere with the person’s ability to understand or communicate. This choice warrants significant consideration and should be based on studying complete information about the person’s condition and about the drug being recommended.

Should Antibiotics Be Used?

Antibiotics fight bacterial infections. Bacterial pneumonia and urinary tract infections are common in people who are dying. If someone is dying, giving antibiotics probably won’t prevent or prolong death, and it could make the person feel more comfortable. However many antibiotics have side effects, so the value of trying to treat an infection in a dying person should be weighed against any unpleasant side effects.

What If the Patient Has a Pacemaker?

A pacemaker is a device implanted under the skin on the chest to keep the heartbeat regular. It will not keep a dying person alive. However, an implantable cardioverter defibrillator or ICD – a kind of pacemaker that also shocks the heart back into regular beats when needed – should be turned off at the point when life support is no longer wanted. This can be done without surgery.

As the patient gets closer to death, the shocks provided by the ICD may no longer bring back a regular heartbeat. Depending on how the ICD is programmed, the shocks may occur more frequently. At the point when repeated shocks become uncomfortable, some patients with ICDs prefer to turn off the shocks. This can be done by a doctor or other health professional placing a special magnet on the outside of the chest to turn off the device. Some ICDs also have a pacemaker. The pacemaker can be left on while the shocks are turned off.

Does the Medical Staff Know the Patient’s Wishes?

As soon as a patient or their agent voices uncertainty about CPR, breathing or feeding tubes, the healthcare provider-in-charge should be told of this. The healthcare provider will discuss the situation with the patient or agent and write on the patient’s chart using terms such as DNR (Do Not Resuscitate), DNAR (Do Not Attempt to Resuscitate), or DNI (Do Not Intubate). These orders are not permanent, and they can be changed if the situation changes.

If you are caring for a dying person who’s living at home, check with your state concerning the need for a “non-hospital DNR.” In many states, emergency medical technicians (EMTs) are legally required to perform CPR and similar techniques when called to a home where someone’s heart has stopped beating. A “non-hospital DNR,” signed by the dying person’s health care provider, may be needed to allow the EMTs to not do CPR.

Hospice staff can help determine whether a medical condition is part of the normal dying process or something that needs the attention of EMTs, and how related choices may affect insurance coverage for care.

Remember: DNR orders do not stop all treatments. They only mean CPR and a ventilator will not be used.

Will Refusing Treatment Cause the Family Legal Trouble?

Choosing to stop treatment that is not curing or controlling an illness, or deciding to not start a new treatment, is completely legal whether the choice is made by someone who is dying or by the health proxy. Some people think this is like allowing death to happen. The law does NOT consider refusing such treatment to be either suicide or euthanasia (intentionally ending someone’s life to relieve pain and suffering).

What If a Health Care Provider Disagrees with Family Members?

Sometimes medical staff, the patient, and family members disagree about a medical care decision. This can especially be a problem when the dying person can't tell health care providers what kind of end-of-life care he or she wants.

If there's an advance directive that explains the person's preferences, those guidelines should determine care. If a health care proxy who understands the patient's wishes has been identified, his or her decisions should be respected. If there's disagreement and no advance directive or health care proxy, it may be necessary to get a second opinion from a different health care provider or to consult the ethics committee or patient representative, also known as an ombudsman, of the hospital or facility. An arbitrator (mediator) can sometimes help people with different views reach agreement on a plan. All of this is stressful for everyone involved. It's much better to have clearly written advanced directives on hand.

What If the Health Care Provider Doesn't Understand the Family's Views about Dying?

America is a rich "melting pot" of different religions, races, and cultures. Traditions and beliefs about the end of life can vary widely. It's important for everyone involved in a dying person's care to understand how family background may alter expectations, needs, and choices.

If there are religious or cultural customs surrounding death that are important to you, tell the healthcare team. Discussing them ahead of time may help avoid confusion and misunderstanding and could ease a dying person's mind.

For instance, many health care providers look to a single person – the dying person or his or her chosen representative

— for important health decisions at the end of life, but in some cultures the entire immediate family takes on that role, something American health care providers may not expect.

Don’t be afraid to say what you want. Each person, each family, is entitled to the end-of-life care that best matches their religious, spiritual, or cultural beliefs. This can include rituals that are important to the patient and family. Make sure you understand how the available medical options presented by the health care team fit or don’t fit into your family’s desires for end-of-life care.

What If Hospitalization Happens?

The healthcare system is a complex machine; a dynamic system with myriad working parts, all of them intertwined and connected. Each year 1 in every 20 in-patients at hospitals will be given a wrong medication, 3.5 million will get an infection from someone who didn’t wash his or her hands or take other appropriate precautions, and 195,000 will die because of mistakes made while they’re in the hospital.

The Institute of Medicine published a groundbreaking report, *To Err Is Human,* in 2000 that attributed as many as 98,000 deaths each year to medical errors. This results in enormous costs across the healthcare industry, from the $29 billion a year in financial damages, to the loss of collective patient trust that comes with a broken Hippocratic Oath. As patients’ health needs increase in complexity, coordination of services between and across disciplines takes greater precedence than ever before.

It’s estimated that a typical patient may encounter 50 different healthcare providers over a four-day hospital stay, including physicians, nurses, and numerous support staff. Each member of the team has specific patient care goals in the larger context of the one goal to provide optimal care. Each role is essential and each is supposed to be complementary.

The only way to combine these separate orbits into an integrated approach to supporting the person who is hospitalized is through assertive questioning, filtering and clarifying by one consistent support person who stays on top of all that… or two people who communicate well together. This is a major role for family to play. Nurses can contribute to the family’s success by supporting them in their questioning process.

Fair Warning to Hospital Patients and Their Personal Caregivers

In an analysis covering 2004 to 2012, the Joint Commission found that **communication issues were the top reason for death related to a delay in treatment**, and from 2010 to 2012, they were the third highest most frequently identified root cause of sentinel events. Many of these events would have been prevented if appropriate communication had occurred.

Communication is a two-way process that inherently demands questions and clarifications. Communication must happen regularly and often, and in whatever form might be most effective in a given situation (e.g., in-person interactions for complex discussions and in email or text for simple and clear information).

An organizational performance company, in conjunction with the American Association of Critical-Care Nurses and the Association of periOperative Registered Nurses, conducted a multi-year study of hospital communication and published the results in 2005, entitled *Silence Kills.*

The authors identified seven areas in which healthcare providers frequently failed to communicate, even when observing blatant oversights and errors (see table below). Sadly, this research also revealed that fewer than 1 in 10 healthcare workers discussed these concerns with the appropriate person.

Situations Most At Risk for Communication Breakdown

Broken Rules	The act of taking shortcuts at the expense of the patient. Observed by 84% of surveyed physicians and 62% of nurses and clinical staff.
Mistakes	Making poor clinical judgments and oversights. Observed by 92% of physicians and 65% of nurses and clinical staff.
Lack of Support	52% of nurses report 10% or more of colleagues are either reluctant to or refuse to help.
Incompetence	81% of physicians and 53% of nurses and clinical staff report concerns about a provider's level of competence.
Poor Teamwork	88% of nurses report having one or more divisive team member.
Disrespect	77% of nurses and clinical providers work with someone who treats colleagues with condescension and rudeness. 33% report working with someone who is verbally abusive.
Micromanagement	52% of nurses and clinical providers say they work with someone who abuses their authority by bullying, threatening, or forcing a viewpoint.

Source: Maxfield et al., 2005

Why does the highly intelligent healthcare workforce often have trouble communicating? The major obstacles are fear of discomfort, of retribution and of job security. A follow-up study to *Silence Kills,* published in 2011 and entitled *The Silent Treatment,* found that over half of the approximately 2,500 nurses surveyed (169 were managers, the remainder were direct care RNs) either did not feel safe to speak up or they felt they weren't listened to.

So, be aware that you may encounter these dynamics when you are a hospital visitor who's watching over a loved one and trying to coordinate communications.

For these and many other reasons, hospice care is the best choice for helping terminally ill people and their families. For more information, see Step 1 where I go into depth about this choice.

Use Validation Therapy & Rapport with People Who Are Confused or Withdrawn

The final tool for this course is ‘validation’. While we all benefit from being validated by others, ‘validation therapy’ is a form of communication designed for connecting with people who are withdrawn or who have cognitive impairments like dementia. This form was developed by Naomi Feil.

Validation and rapport provide a way to communicate to confused and withdrawn people that they are heard and acknowledged, regardless of whether you actually agree with what they’re saying, and that they are being valued rather than marginalized or dismissed. Below is an example of how you can do this, excerpted from Naomi Feil’s website.

Let’s say you’ve known 90-year-old Elsa for 30 years. When you visit her, she insists that you are her husband and she begs you to take her home. You can guess that she feels alone and wants to be with her husband, with whom she felt loved and needed.

To validate Elsa, first accept her physical condition; her loss of logical thinking, and her loss of normal social controls. Then choose your response to her. Here are five examples of Validation-type techniques to consider when interacting with people who are confused:

- **Center**: When you’re embarrassed or frustrated by the behavior of a confused person, you might become judgmental. If so, you won’t be able to listen to them. You can use the Heaven and Earth breath to ground yourself and clear your emotions so you can perceive the feelings of the other person.
- **Express her emotion for her, based on your best guess:** “Oh Elsa, I’m guessing you miss your husband. You were

so close. I bet you miss him a lot.”

- **Use Polarity – Ask about the extreme:** “What do you miss the most about him?”
- **Re-Phrase:** “You want to be back in your own home. Is that right?”
- **Reminisce:** “I remember when you and John built that house. Do you remember?”

A final resource in this section is the Sacred Dying Foundation (SDF), which works to bring spirituality to the process of dying in hospitals, nursing homes and other healthcare facilities. SDF was created by author, theologian, and educator Megory Anderson. Her book *Sacred Dying: Creating Rituals for Embracing the End of Life* is one of my favorites. It offers an excellent guide to how to be a healing presence for dying persons.

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