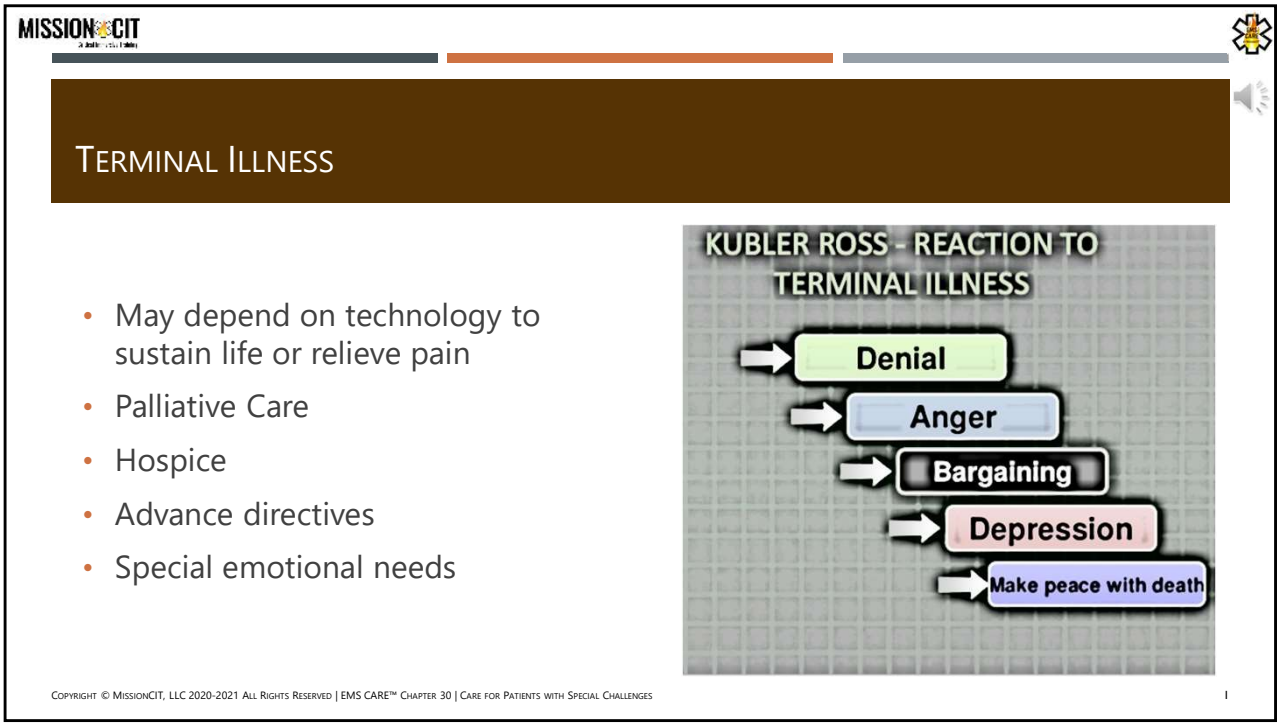


Terminal illness or end-stage disease is an affliction that cannot be cured or adequately treated. Hence, the condition is reasonably expected to result in the death of the patient. This term is more commonly used for progressive ailments such as cancer or advanced heart disease than for trauma.

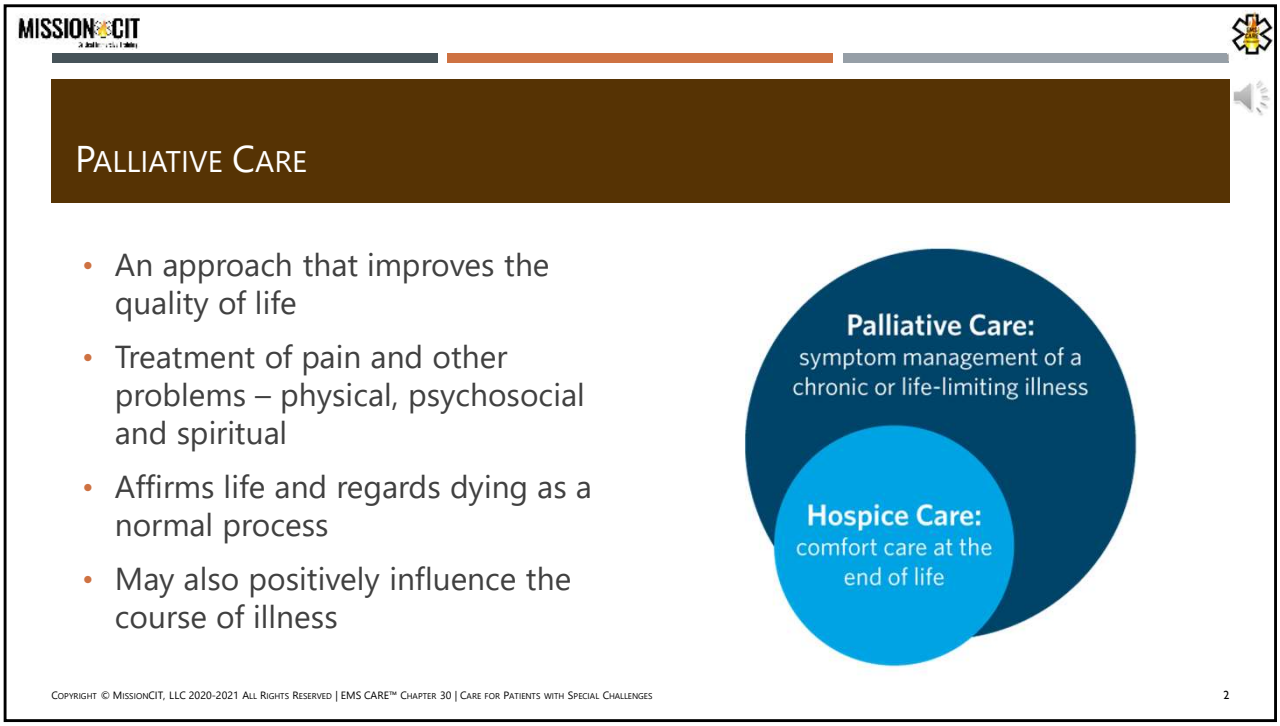
Patients with an end stage disease may be in palliative care at home or in a special care facility. The patient may depend on technology to sustain life or relieve pain. There may be Advance directives in place like a DNR. And likely the patient has special emotional needs.

EMS is frequently sent to these situations even though it is not their core competency. It is often difficult if not possible to provide the required care in a domestic surrounding.

In addition, EMS is often uncomfortable with the emotional and legal aspects of palliative emergencies. Frankly, we are taught how to fix things and not just stand by. But with palliative care, being supportive of family and caregivers as well as adhering to an advance directive is often the right thing to do.

Unfortunately, these situations are seldom easy, and can lead to hospitalization and direct conflict with the patient's wishes. Let's see how to manage these circumstances to the best of our abilities.

In this lesson, we will review Palliative care, Hospice, Advanced directives, and some representative terminal illnesses you may encounter.

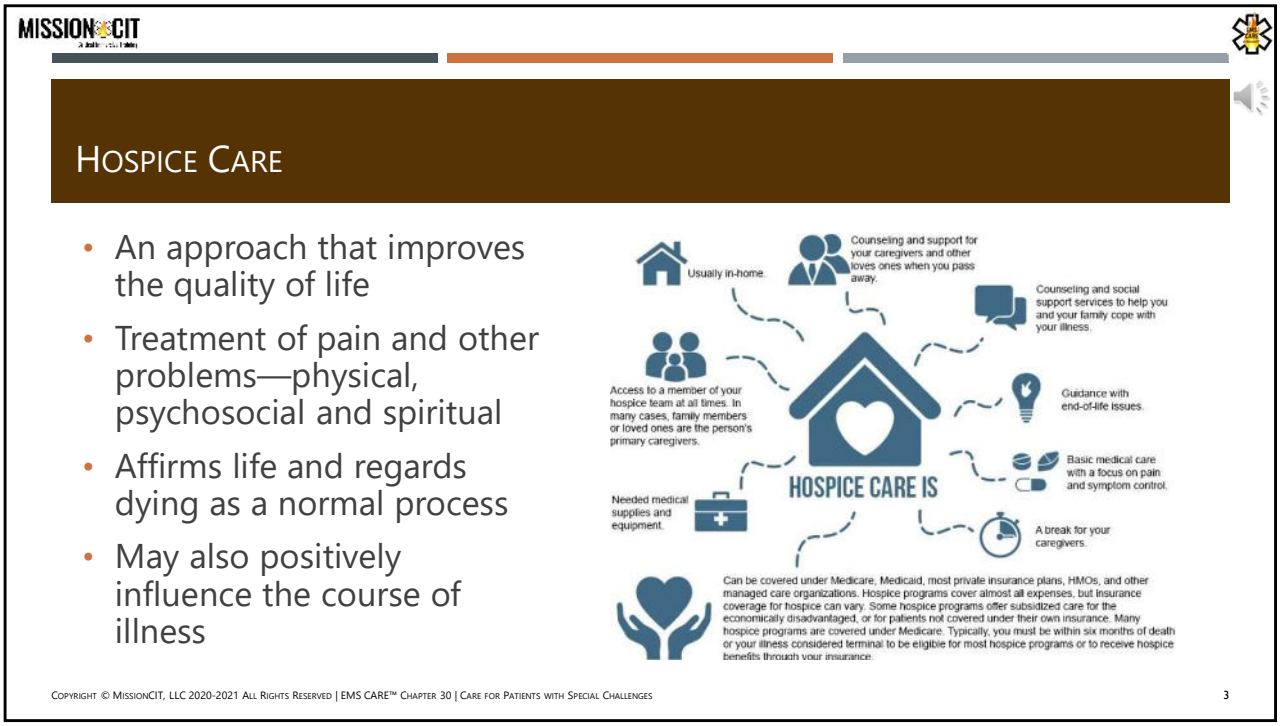


The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families, who are facing the difficulty associated with life-threatening illness. It is done through the prevention and relief of suffering by means of early identification and thoughtful assessment. It treats the person holistically, caring for the physical, psychosocial and spiritual aspects of pain and approaching death."

According to the WHO, these 9 items are the foundation of palliative care:

1. It provides relief from pain and other distressing symptoms.
2. Affirms life and regards dying as a normal process.
3. Does not intend to either hasten or postpone death.
4. Integrates the psychological and spiritual aspects of patient care.
5. Offers a support system to help patients live as actively as possible until death, and helps families cope during the patient's illness and in their own bereavement.
6. Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
7. Enhances a patient's quality of life, and may also positively influence the course of illness.
8. Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy; and
9. Includes investigations needed to better understand and manage distressing clinical complications.

For the EMT, your role may be just supportive, however your actions remain dependent upon scene size-up, assessment, and the presence or not, of advance directives.



So, both palliative and hospice care provide comfort. But palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness.

Hospice care is most often offered only when the person is expected to live less than 6 months, is rapidly declining, and ready to forego treatments aimed at prolonging life.

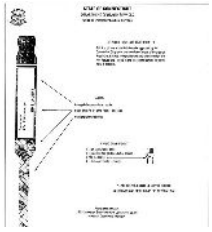
Hence, according to the hospice foundation of America, Hospice is Medical care designed to help someone with

a terminal illness live as well as possible, for as long as possible, increasing quality of life. It includes an interdisciplinary team of professionals who address physical, psychosocial, and spiritual distress, focused on both the dying person and their entire family. And it provides ongoing therapy that addresses symptom management, coordination of care, communication, decision making, and treatment goals.

Often, when a patient is in hospice, there are advanced directives for Emergency Medical Personnel. But not always.

Advance Directives

- Durable power of attorney for health care
- Living will
- DNR Orders, Bracelet
- POLST & MOLST
- Notification Card
- Local Protocols
- CT Protocol 6.7






STATE OF CONNECTICUT
DEPARTMENT OF PUBLIC HEALTH

TRANSFER OF "DO NOT RESUSCITATE" ORDER

Name_____Identification Number_____

Healthcare Institution_____

I, the undersigned, attest that the above named person has a valid "Do Not Resuscitate" order which was written on_____

by_____, M.D. and is retained in this person's medical record at the above location.

Signature of MD or RN | Printed Name | Date

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4

Note: this is a long slide – and very important. Be sure to read the text. So, According to the NIH, there are two main elements in an advance directive; a living will and a durable power of attorney for health care. There are also other medical documents that can supplement the advance directive.

For the EMT, know that there are documents specifically created to alert emergency medical personnel of the patient's wishes regarding measures to restore cardiac function or breathing. They include do not resuscitate orders, and POLST and MOLST forms. These are

Physicians Orders or Medical Orders for Life Saving Treatment.

EMS personnel need to be alerted of the presence by the caregiver or family, and be presented with a valid non-hospital DNR order, or POLST or MOLST form.

Most importantly, if you are presented with an Advance Directive Notification card, know how to manage per local protocol. Then, be sure to know how to proceed if you are verbally instructed but have no physical proof of the directive. Lastly, if presented with a valid directive, but the family wants you to proceed with care despite the order, know what to do before faced with the situation.

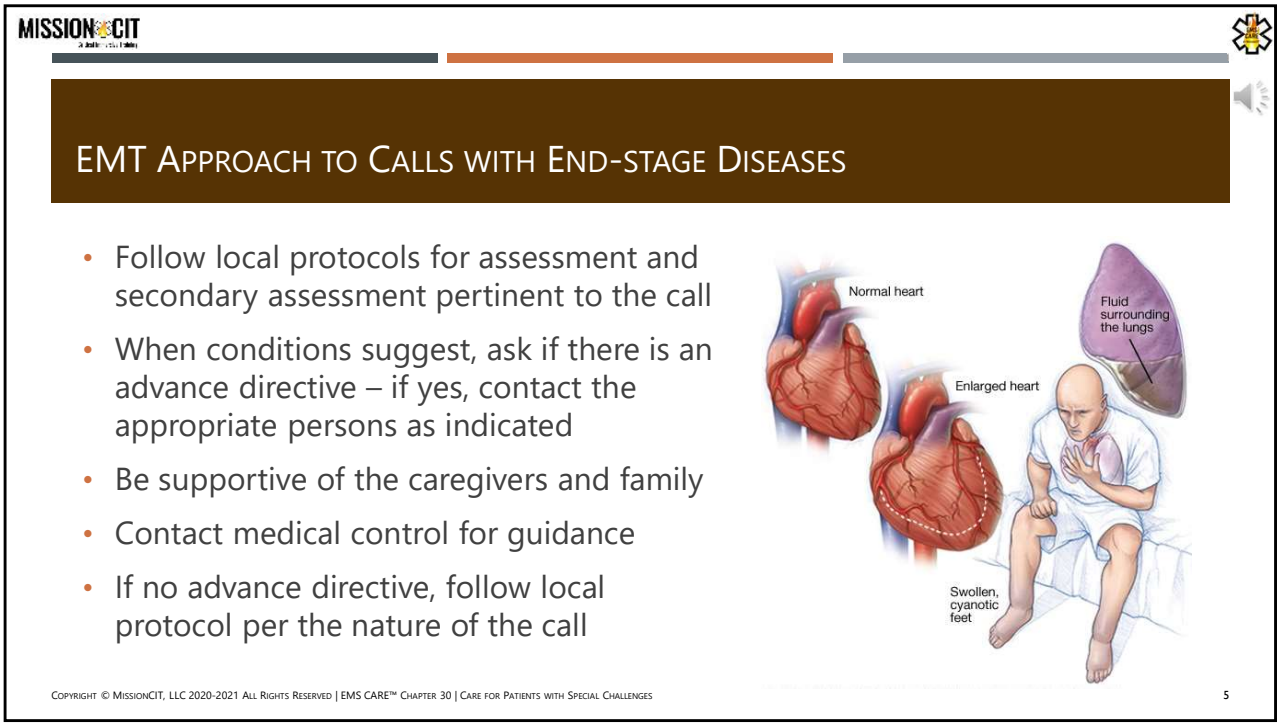
For EMTs in the state of Connecticut, Protocol 6.7 for do not resuscitate orders states: The following are the only recognized DNR options in Connecticut and must be presented to the EMT.

1. Statewide DNR, transfer form documenting the patient's name and signed by a physician or R N and that clearly documents the DNR order, or
2. A do not resuscitate bracelet approved by Connecticut DPH worn by a patient, inscribed with both the patient and physician's names. Note that the bracelet should be affixed to the patient and

shall not appear to be broken or cut.

3. You must have a valid DNR order, do not resuscitate transfer form, or DNR bracelet. Neither an Advanced Health Directive or a Living Will, may be treated as a do not resuscitate order.
4. In addition, On June 26, 2017, the use of MOLST forms was approved in Connecticut.

For CT EMTs, you should be fully familiar with Protocol 6.7 found on pages 120-121 of the CT EMS protocols version 2017 point 2 as well as the protocol for MOLST and your local medical directives.



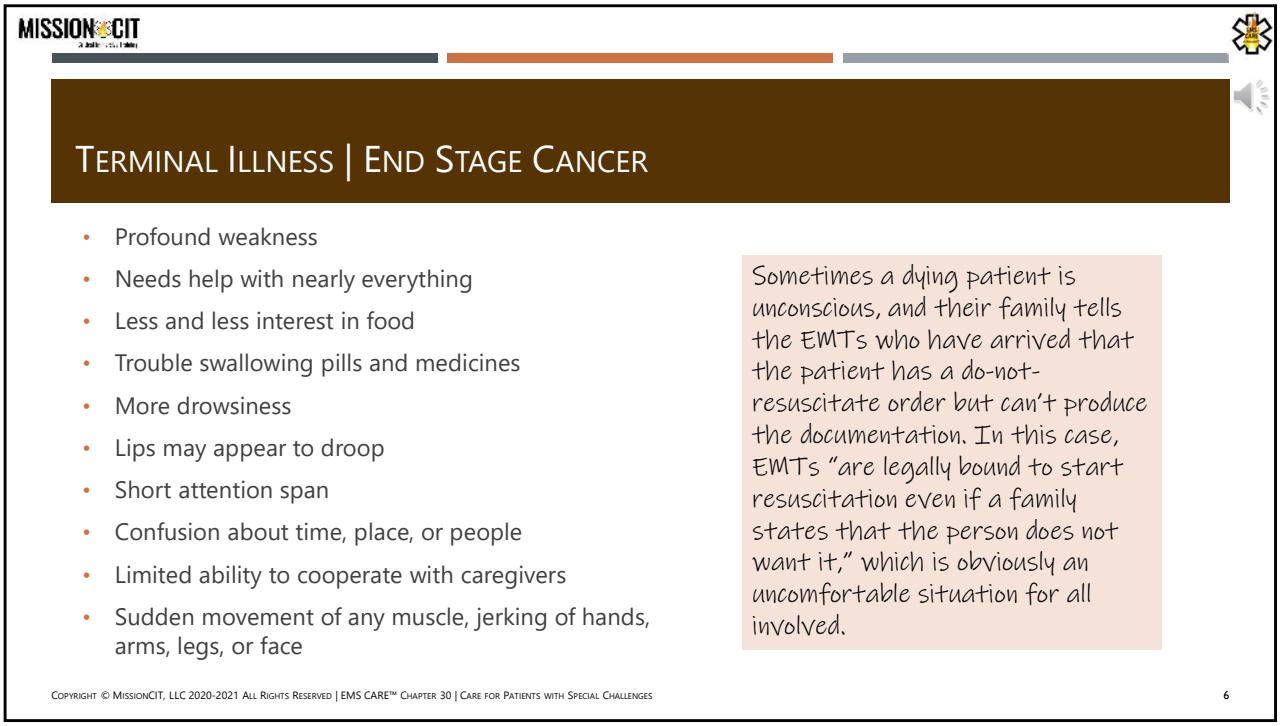
When presented with a terminally ill patient, the EMT may approach the call as follows.

1. Follow local protocols for assessment and secondary assessment pertinent to the call.
2. When conditions suggest, ask if there is an advance directive – if yes, contact the appropriate persons as indicated or proceed per local protocol.
3. Be supportive of the caregivers and family.
4. If appropriate, Contact medical control for guidance. and
5. If no advance directive, follow local protocol per the

nature of the call.

We next speak to several terminal illnesses you may encounter when on scene. They are, End-stage cancer, Heart failure, Kidney failure, Huntington disease, and Lou Gehrig disease.

At the end of each of these diseases, we add a situational consideration to think about.



According to the American Cancer Society, end stage cancer patients may have the following changes in body function:

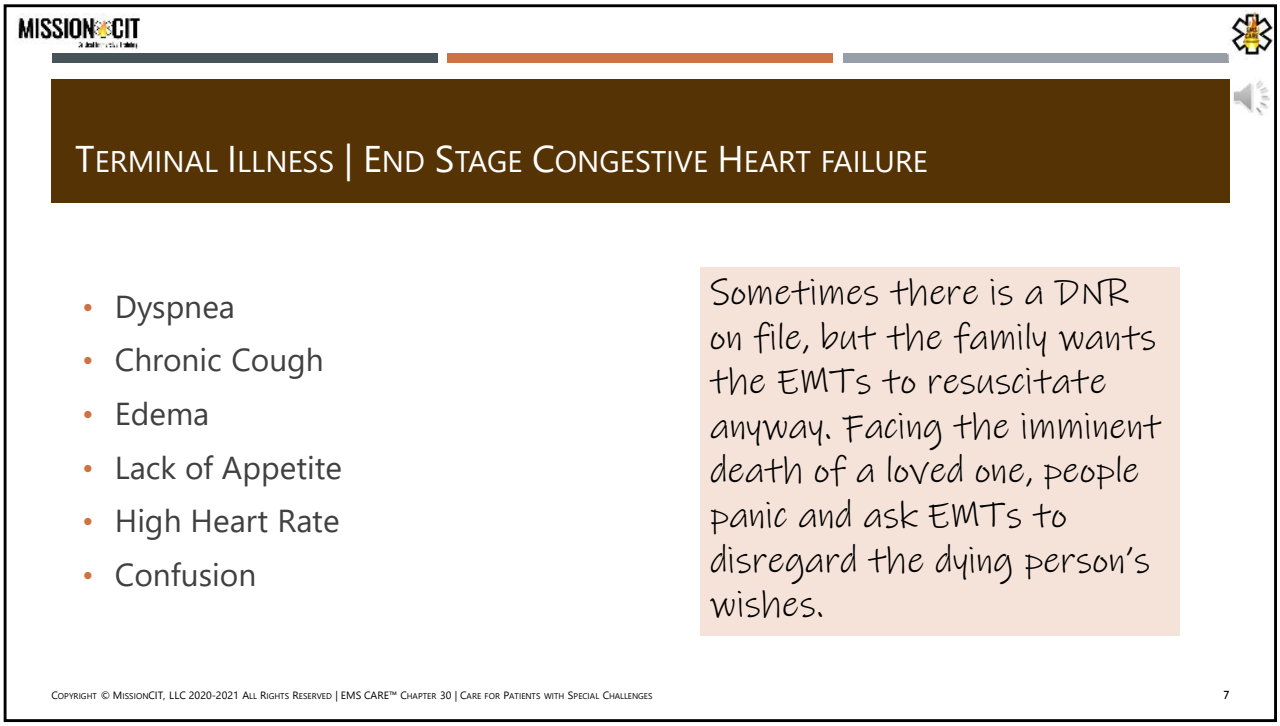
1. Profound weakness – usually the patient can't get out of bed and has trouble moving around
2. Needs help with nearly everything
3. Less and less interest in food, often with very little food and fluid intake for days
4. Trouble swallowing pills and medicines
5. More drowsiness – the patient may doze or sleep much of the time if pain is relieved, and may be hard

to rouse or wake

6. Lips may appear to droop
7. Short attention span, may not be able to focus on what's happening
8. Confusion about time, place, or people
9. Limited ability to cooperate with caregivers, and
10. The sudden movement of any muscle, jerking of hands, arms, legs, or face

And here is the first situational consideration.

- Sometimes a dying patient is unconscious, and their family tells the EMTs who have arrived that the patient has a do-not-resuscitate order, but can't produce the documentation. In this case, EMTs "are legally bound to start resuscitation even if a family states that the person does not want it," which is obviously an uncomfortable situation for all involved.



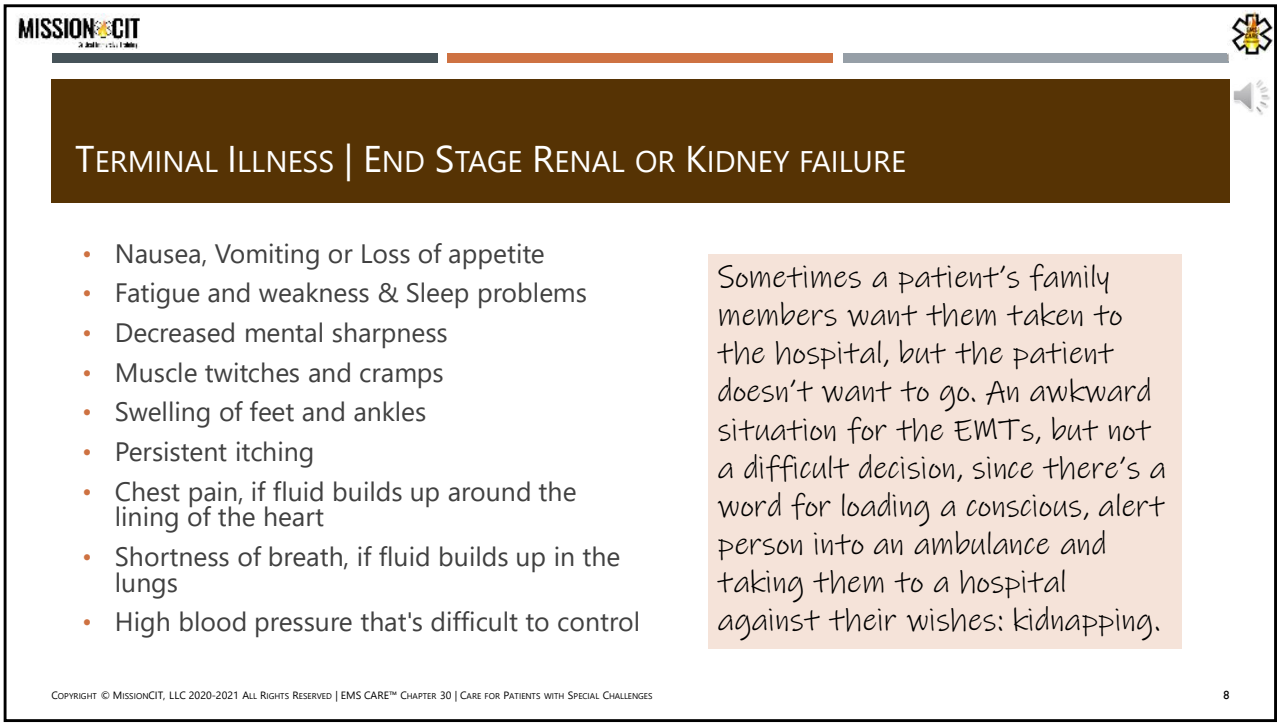
Symptoms of end stage congestive heart failure may include

1. Dyspnea – or shortness of breath – can occur both during activity and rest. This is the symptom that often sends patients racing to the hospital or calling EMS late at night.
2. Chronic Cough - When the heart cannot keep up with the supply of blood moving between it and the lungs, fluid can build up in the lungs. This results in a chronic cough or wheezing that can produce white or pink mucus.

3. Edema - As the heart's ability to pump slows down, fluid can build up in the body. This creates swelling in the extremities – particularly the feet, ankles, legs, or abdomen.
4. Lack of Appetite - As the digestive system receives less blood, patients may feel full or nauseous. Not wanting to eat is a natural part of the body shutting down, but families often find this distressing.
5. High Heart Rate In response to a loss in pumping capacity, the heart begins to beat faster. The patient experiences this as a racing or throbbing heartbeat.
6. Confusion - When the heart stops working effectively, it can change sodium levels in the blood. This leads to memory loss, confusion, and a general feeling of disorientation.

And here is the second situational consideration.

Sometimes there is a DNR on file, but the family wants the EMTs to resuscitate anyway. Facing the imminent death of a loved one, people panic and ask EMTs to disregard the dying person's wishes.



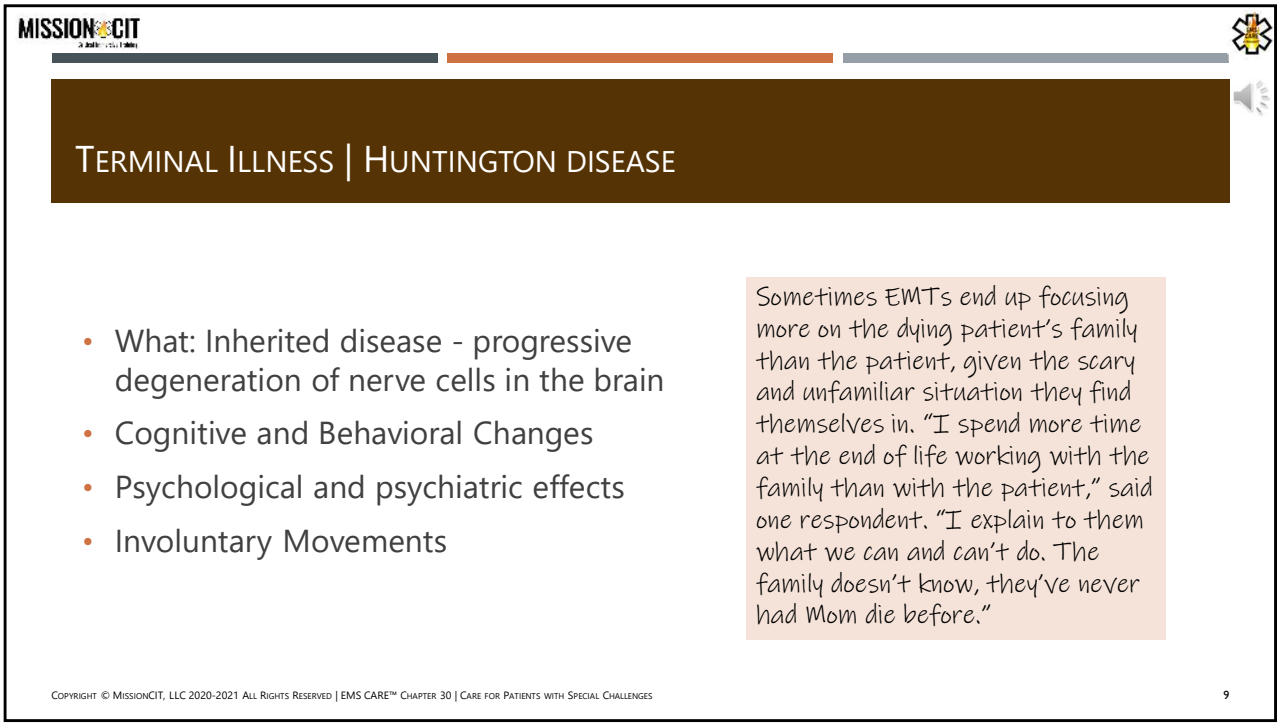
According to the Mayo Clinic, patients with end stage renal disease require dialysis or a kidney transplant to stay alive. If the patient chooses not to pursue those options, or if they are no longer viable, the patient may exhibit the following symptoms:

1. Nausea, Vomiting or Loss of appetite
2. Fatigue and weakness & Sleep problems
3. Decreased mental sharpness
4. Muscle twitches and cramps
5. Swelling of feet and ankles
6. Persistent itching

7. Chest pain, if fluid builds up around the lining of the heart
8. Shortness of breath, if fluid builds up in the lungs
9. High blood pressure that's difficult to control

And here is the third situational consideration.

Sometimes a patient’s family members want them taken to the hospital, but the patient doesn’t want to go. An awkward situation for the EMTs, but not a difficult decision, since there’s a word for loading a conscious, alert person into an ambulance and taking them to a hospital against their wishes: kidnapping.



Huntington's disease is a rare, inherited disease that causes the progressive degeneration of nerve cells in the brain. Huntington's disease has a broad impact on a person's functional abilities and usually results in movement, cognitive and psychiatric disorders.

According to the Huntington Disease Society of America, there are several mid and late stage symptoms you may encounter covering Cognitive and Behavioral Changes, Psychological and psychiatric effects and Involuntary Movements. You can read more in the text that follows.

And here is the fourth situational consideration.

Sometimes EMTs end up focusing more on the dying patient's family than the patient, given the scary and unfamiliar situation they find themselves in. "I spend more time at the end of life working with the family than with the patient. I explain to them what we can and can't do. The family doesn't know, they've never had Mom die before."

Cognitive and Behavioral Changes

- Mid Stage: Irritability, apathy, little patience, anger, aggressive behavior
- Late Stage: Impaired judgment, unawareness of symptoms, apathy and withdrawal are all signs of increasing dementia.

Psychological and psychiatric effects

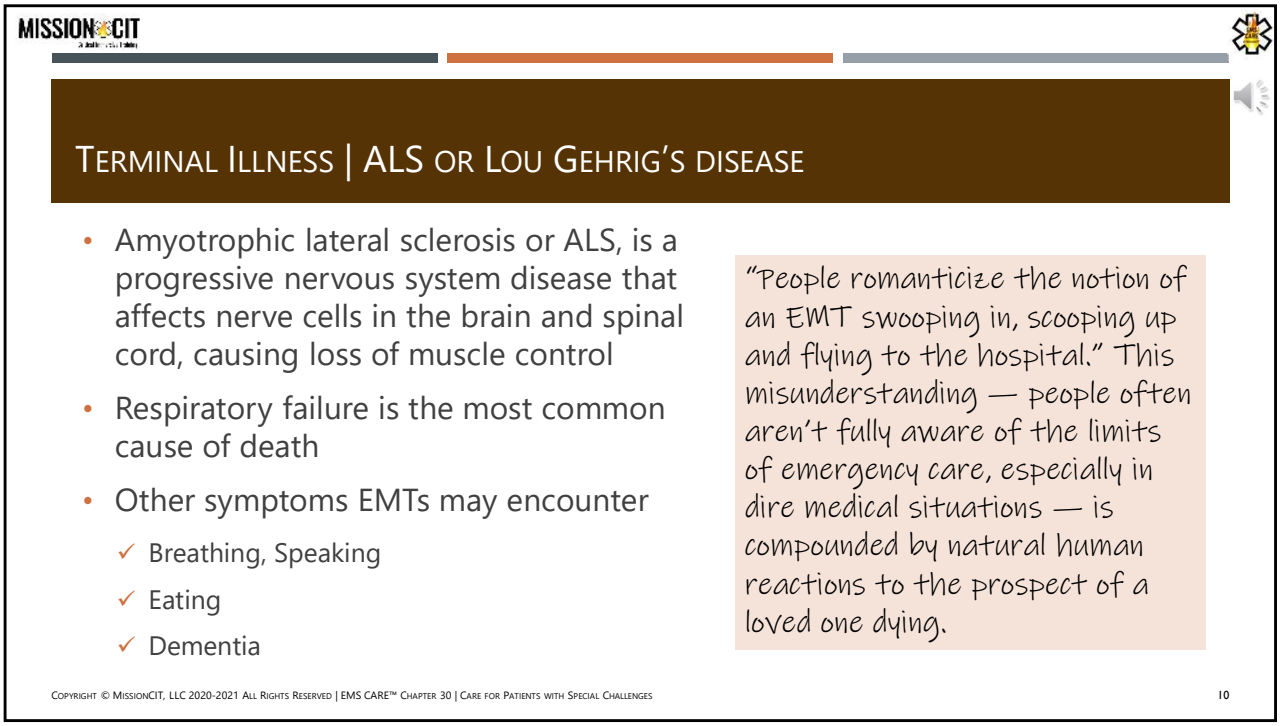
- depression, anxiety, irritability, obsessiveness and compulsiveness,
- perseveration, unawareness, impulsiveness, bipolar disorder,
- psychosis, or schizophrenic-like symptoms

Involuntary Movements

- Mid Stage: Twitching or jerking movements of the

head, arms, and legs, difficulty walking, falls

- Late Stage: Movements become increasingly difficult to control, Severe chorea – require anti-tipping wheelchair



Amyotrophic lateral sclerosis or ALS, is a progressive nervous system disease that affects nerve cells in the brain and spinal cord, causing loss of muscle control. Eventually, ALS affects control of the muscles needed to move, speak, eat and breathe. There is no cure for this fatal disease. The most common cause of death for people with ALS is respiratory failure.

As the disease progresses, ALS causes complications, such as breathing, speaking and eating problems as well as dementia. You can read more about the details in the text that follows.

And here is situational consideration number 5.

“People romanticize the notion of an EMT swooping in, scooping up and flying to the hospital.” This misunderstanding — people often aren’t fully aware of the limits of emergency care, especially in dire medical situations — is compounded by natural human reactions to the prospect of a loved one dying.

So that’s a somber end to this lesson. Remember, we can only do our best. Be sure to take care of your own emotions after a terminal illness call as you need to be ready for your next patient.

Missah will be with you next to discuss how Environmental Considerations affect care for patients with special challenges.

Good Studying

Breathing problems: Over time, ALS paralyzes the muscles used to breathe. Patients may be given continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP) to assist with breathing at night. Other ALS patients choose to have a tracheostomy for full-time use of a respirator that inflates and deflates their lungs.

Speaking problems - people with ALS often rely on other communication technologies to communicate

Eating Problems – patients develop malnutrition and dehydration from damage to the muscles that control swallowing.

Dementia: problems with memory and decision-making.