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PASTORAL CARE AT THE END OF LIFE

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by Peter Lutz, MD

Introduction

Hello and welcome to the Pastoral Care at the End of Life Module

My name is Peter Lutz. I am a fellow minister in the New Apostolic Church. I am also a practicing physician who specializes in intensive care medicine. In addition, I also serve as a medical director for one of our local Hospice organizations.

Today we are going to talk about some of the issues you may encounter in your ministry while providing pastoral care to members and their families at the end of life or at the time of death.

By the end of this course, you will be familiar with some of the ethical and spiritual questions that can arise at this time in a person's life. You will also be more familiar with some of the terminology that medical professionals use during this time

In addition, you will be aware of some of the issues that can arise within families that can add to the stress of these situations.

This course will not make you an expert in end of life pastoral care, however by the end of it you will be better equipped to be a blessing in your ministry and to your members. These are very stressful and emotional times in lives of our members and their families. And in my professional life, I have seen ministers be an incredible comfort and support to dying patients and families. Unfortunately, I have also seen well-intentioned but inexperienced ministers create chaos and add to the pain.

Physical death is a universal part of life and is something we will all experience ourselves, as well as in the circle of our families and congregations. As it says in the Bible:

For dust you are, And to dust you shall return. (Genesis 3:19)

Therefore, just as through one man sin entered into the world, and death through sin, and so death spread to all men, because all sinned. (Romans 5:12)

As New Apostolic Christians, we know that a person is made up of a physical body, along with a soul and spirit. While the soul and spirit are eternal, the physical body will one day die and return to the earth.

Then shall the dust return to the earth as it was: and the spirit shall return unto God who gave it. (Ecclesiastes 12:7)

The time around someone's death can be a very stressful time for them and their family. Even for believers, this is a time that can pose difficult questions and provoke anxiety and fear. Decisions may need to be made that are difficult, both intellectually and emotionally. As a minister, you may be called upon to be a support and even provide counsel during this hard time. In that capacity, we have the great opportunity to be a healing and comforting presence. Or, if we are not sensitive and careful, we can potentially make a difficult situation even worse. It is also important to have some understanding of some of the medical terminology and issues that come up at the end of life, in addition to our doctrinal beliefs, so that we can understand and support members through these times in their lives.

Background: Dying in the USA

When asked how most people picture their death, there are some universal desires. Most people envision themselves remaining vibrant and active right up to the very end of their life. They then wish to die in their sleep unexpectedly or quickly, while enjoying life. Others have a different vision where they drift off into a final sleep at home in their own beds, surrounded by loving family. When we stop and look at some of the statistics surround death in the US, the truth of how we die is very different:

- Only about 10% of people die unexpectedly and suddenly. 90% of us die after a decline or in some other predictable fashion.
- For those over age 65, only about a quarter die at home. The vast majority die in either the hospital or a nursing home.

- Across the board in America, One in five of us will die after being admitted to an ICU. Of these, 85% take place once a decision has been made to stop or withhold further medical care

So what does this mean? The majority of our members will not die unexpectedly, but will die after some decline or change in health status that will occur over days to years. Over half will die in a medical setting like a nursing home or hospital. For most of these members, death will come after they themselves, or their families, had to make hard decisions in relation to their medical care. These decisions can be difficult and heart wrenching.

It is also important to note that our members may have unrealistic expectations of the abilities of modern medical care. Multiple surveys of the population have brought out that most of us get our medical information from watching fictional TV programs.

The success rates of heroic life-saving measures like CPR on TV are much better then what happens in real life. For example, the success rate for CPR on TV programs is around 75%. In reality, the success rate is less than half that at 30%, with survival rates being even worse for those who have CPR started outside the hospital.

On TV, of those who had to receive CPR, about 2/3rds survived to go home from the hospital. In reality, the long-term survival rates are only about 1/3 and in elderly patients, only about 5%.

On TV, most of those who suffer cardiac arrest are young and the major causes are trauma or a single issue. This may lead to the mistaken belief that CPR is equally effective across all ages. The reality is that the older the patient is and the more underlying medical problems they have, the less likely they are to survive cardiac arrest and CPR.

Outcomes of CPR on TV are usually portrayed in a very binary fashion, either full recovery or death. In reality, most people who suffer a cardiac arrest and require CPR will have some long-term disability or problems afterwards.

Pastoral Care for End of Life

Support for a dying person requires a very special relationship of trust and confidence, and means being able to sympathize with their situation. These meetings may take the form of a conversation characterized by truth or a silent, wordless presence. Love does not need words to reach a dying person. A companion seeking to convey such love will intuitively feel what the dying person needs.

As ministers, our role should be:

- To offer prayers for the affected member and their family, both in our own prayer life and in the circle of the affected family.

- To be a sounding board as they work through these decisions.
- To realize the basic ethical principles the medical profession uses in the approach to these issues.
- To be a source of information on doctrinal questions that may arise.
- To understand and accept the grief of the dying person in the various phases of death.
- To identify and respond to the needs of the dying person.
- To display great sensitivity in recalling the comfort inherent in our faith.
- To build up a special relationship of trust and confidence with the dying person in order to support them truthfully, competently, and effectively. A “white lie” is of no use.
- To help the dying person recover their inner peace and calm.
- To celebrate Holy Communion with the dying person so that they can depart from this world into the next world in peace. And…
- To support the dying person’s relatives for as long as necessary and with the requisite intensity and consolation.

As ministers our role **should not be**:

- To insert ourselves into personal or family discussions around these issues without being asked. These can be intensely personal issues.
- To trivialize the dying person’s fears or to interpret them as unbelief or lack of faith. Even for strong believers, this can be a time of fear and uncertainty.
- To make these decisions for them. These important decisions are best made by the dying member or their family.
- To promise a miracle. Remember, a miracle is only a miracle because it is an exceedingly rare outcome. The Bible does show that a person’s faith is necessary for a miracle, however, their faith alone cannot command the Lord to do one. The dispensation of a miracle is fully in the hands of the Lord and will only happen if it fits in with God’s plan for that person, no matter how deep our faith. While we pray for God’s help with healing and, if possible, a full recovery, we must always leave it as “not [our] will, but Yours, be done,” even as Jesus Himself did in the Garden of Gethsemane.

A Death in the Family

The impending death or the death of a loved one is a large strain on the family. Problems that have long laid dormant and unreconciled tend to reappear and assert themselves during these times. Often family members will try to enlist us on their side in the difficulties. However, as ministers, we need to be sensitive to this and strive to guide the affected members towards reconciliation, while not taking sides.

Some examples of situations that tend to flair during these times are:

- True or perceived favoritism toward one child or another. Where one child thinks Dad or Mom always liked you best.
- Sibling rivalries
- Financial concerns over how to pay for medical care and fights over inheritance; and
- Long standing fights or feuds that now take on more urgency with the possibility that they may never be resolved due to the death
- Who has the right to make decisions on the loved one's behalf
- A common scenario here is a schism between those that live near and normally care for the loved one versus those that live out of town and do not frequently care for the person or has not appreciated their decline.
- This may be a case where our conflict resolution program can be very beneficial.

To help us understand some of emotional and doctrinal issues that surround end of life, we will now present a set of pastoral care scenarios that illustrate these issues. At the end of each one, we will then discuss the question or questions that each scenario presents. As we present each scenario, imagine yourself as the minister in the conversation and consider how you would respond to the member asking the questions.

SCENARIOS

Scenario 1: Brain Death

You are finishing your day at work late one afternoon when you receive an urgent call by your fellow priest in the congregation where you serve. His 44-year-old wife has been involved in a head-on collision this morning while out running errands. She is lying unresponsive on a ventilator in the ICU. The doctors said she has a severe head injury, but your fellow priest is waiting on a neurosurgeon to evaluate her to see if anything can be done. He wants you to come and be with him and their three children (ages 8, 11, 16) when they get the report from the doctor. You head right over to the local hospital and sit with them until the doctor arrives.

The doctor does not have good news. The priest's wife has severe bleeding in her head, causing irreparable brain damage. Based on the exam by the neurologist, neurosurgeon, and medical doctor, they conclude she is brain-dead and will not recover. The only thing keeping her body alive right now is the ventilator (life support machine). They recommend stopping the ventilator and other medicines and letting her go.

Your fellow priest is obviously very upset and distraught. In his grief, he asks you, "If the machine is keeping her alive, am I killing her by letting them turn it off?" He also has been looking at a pamphlet concerning organ donation in the waiting room and is wondering if this is Ok with our faith as he thinks his wife would have wanted to donate her organs if they could help someone else. Consider how you would respond.

Discussion:

Cardiac death occurs as a result of loss of heart function when the heart cannot be restarted. Brain death normally occurs in this situation a few minutes after the irrevocable cardiac arrest. The brain is the main control center of the body and after its death, all organs and tissues inevitably die. Brain death is defined by the irreversible cessation of all brain functions. In certain cases of brain death, cardiovascular function, heart beating and breathing, can still be artificially maintained by mechanical ventilation.

From a medical and legal standpoint, brain death equates to actual death, even if the rest of the body is maintained on life support. The church shares this view. So in this case, the injured sister is considered dead, even though her heart and lungs are still being maintained. Thus, you would not be killing her by letting them take her off ventilator; she is already dead.

Many times, patients in this condition may be considered for organ donation if the family agrees. The process in these cases would be to maintain the patient on the ventilator until the patient is prepped for the donation. They then disconnect the patient from the ventilator until cardiac death

occurs and then immediately start the harvest of the appropriate organs. This practice is also not contradicted by our faith or our understanding of death. There is no sin involved in allowing this to take place if the family wishes, and may actually be a point of grace and blessing in allowing some good to come out of the loved one's death.

Scenario 2: Living Wills

A 67-year-old elderly sister asks you to visit her at home. During the visit, she notes that old age is hard. She is gradually having increasing problems caring for herself due to her arthritis and other chronic medical problems. She states, “I am okay for now, but I know one day I won’t be able to care for myself.” She has thought a lot about how her life will end and she is convinced that she would never want to be stuck on a life support machine or have to be fed through a tube. Given all this, she wants to make a living will and is about to see a lawyer to get one made. She has decided that if her heart stops, she does not want CPR or other heroic measures. She does not want to be fed via a tube if she can’t eat on her own. The sister asks you if the church supports living wills. Is it like committing suicide to decide to one day not have these life-saving measures?

Discussion:

Man was made in the image of God with free will to choose what is right for them in their life. This does not only apply to spiritual matters, but to all matters of life.

In the study of Ethics, man is said to have autonomy. Autonomy is defined as “the right of competent adults to make informed decisions about their own life and medical care.” That means we can say what we do or do not want done in our medical care. In this sister’s case, she has thought about what kind of medical care she would want when her health eventually declines, and she has decided that she wishes to draw the line at these heroic measures. Personal autonomy even says a person has a right to choose a path not recommended by their doctors or even family members or other reasonable people, as long as they understand the consequences of their choices.

These decisions are not fixed in time and a person is allowed to change their mind. For example, a 35-year-old in good health may well opt for heroic measures to maintain their natural life, while at 80 years old and in poor health, opt against them.

A person can also change their mind during the course of an illness. For example, a patient with cancer while undergoing treatment that is difficult and not progressing well, may say, “I want to continue treatment, but if I get ill enough for my heart to stop, then I don’t want to be resuscitated.” But, then several months down the road, if they pull through and have a full recovery, may change their mind in the presence of a routine, but severe pneumonia because it is curable and they had previously been back in good health.

The next thing to consider is if opting out of life-saving measures is like committing suicide. What is suicide? It is the taking of one’s own life via some active means when you would have otherwise gone on living. The main point here is that suicide is an active intervention (such as shooting oneself, taking an overdose, etc.) to end one’s life prematurely. Deciding not to fight the natural process that will eventually end a person’s life (i.e. age, incurable disease, debility), is not considered suicide, as you are not doing anything active to prematurely promote your death, you are just not actively preventing it. You, as in this case, are waiting on the Lord’s will for your time of death, not setting it yourself. So a living will is not considered a form of suicide.

A living will, also called a directive to physicians or advance directive, is a document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions when the time comes. It has no power after death. It can give invaluable guidance to family members and healthcare professionals if a person can't express his or her wishes. Without a document expressing those wishes, family members and doctors are left to guess what a seriously ill person would prefer in terms of treatment. They can even end up in painful disputes, which occasionally make it to a courtroom.

The living will is usually a legal document, either made by the patient themselves and executed with a notary or created with the help of a lawyer. The requirements on how to create one of these can vary state to state.

It must be noted that living wills are only truly good when they are accompanied by conversations with the family. If the family does not know of or agree with the living will, then they are very likely to go against it once the person can no longer make their own decisions. Once you become unable to voice your own opinion, your next of kin can now say what occurs to you. Your living will only stands if they know about it and support it, so you must discuss it with them and make sure they understand your wishes and are willing to uphold them.

The church supports a member's right to make decisions in regards to their medical care and supports living wills as according to the doctrine of the New Apostolic Church.

Scenario 3: Choosing not to Start Care

There is a 77-year-old retired priest in your congregation. Over the last couple of years, his health has slowly declined. He has problems with his heart and lungs that limits his mobility, requiring him to use a walker to get around. He had to move in with his daughter a couple of years ago when he was no longer able to live by himself. His daughter brings him to service every Sunday, where he shuffles in and sits near the back. He takes Holy Communion in his seat and the members visit with him there after service.

One Sunday he asks you if you could pay him a home visit, which you cheerfully agree to. The following Tuesday evening you visit together in the small sitting area of the in-law suite in his daughter's home. He tells you that a couple of weeks ago he began to have some pain in his stomach. His doctor did some tests and found a growth on his liver. Further tests showed a large mass in his lung that turned out to be cancer that had spread to his liver. He saw an oncologist who confirmed that he had advanced cancer. Chemotherapy was offered, but they expect there to be significant side effects, including long-term worsening of his weakness and further loss of his mobility. Without chemo, they give him 6 - 9 months to live. Chemo would only add about 1 - 3 months more. He feels in his heart that he would lose a lot of his quality of life to the chemo that he would not get back, all just to get a few extra months.

He says, "I have had a good life and feel the Lord has blessed me richly in it. For all that, I am very grateful and thankful to the Lord. If I only have a few months of it left, I would rather spend it at home with my family and not in doctors' offices or hospitals. They tell me I can enter a hospice program that would be able to help control my pain or other symptoms as they arise, with the goal of keeping my quality of life as good as they are able. That is what I want to do. Is it wrong for me to not want to fight this thing and just be comfortable for as long as possible?" Consider your response.

Discussion:

Many of the same ethical and spiritual principles come into play in this situation as in Scenario 2. Each member has the right to choose what is best for their health and life. Specifically, this illustrates the principal of **WITHHOLDING** medical treatment. This is considered ethical, as long as it reflects the member's values. In this case, the priest has decided that the possible effects of continued treatment would be too fatiguing physically and not worth the expected benefit of an additional 1-3 more months of life. Once again, this is not considered suicide and is considered ethical as it upholds the principle of personal autonomy, it allows the natural processes to bring about death, and we are not actively causing their death.

What is hospice? Hospice offers medical care toward a different goal: maintaining or improving quality of life for someone whose illness, disease, or condition is unlikely to be cured. It is essentially a change in the mindset of care for the patient. In standard medical care, the overarching goal is prolonging a patient's life over that of comfort, and even at times, quality of life. Once hospice is started, extending life is now no longer the primary goal, and now comfort and quality of life take precedence over all. Each patient's individualized care plan is updated as needed to address the physical, emotional, and spiritual pain that often accompanies terminal

illness. Hospice care also offers practical support for the caregiver(s) during the illness and grief support after the death. Hospice is something more that is available to the patient and the entire family when curative measures have been exhausted and life prognosis is six months or less.

The church supports a member's right to choose what medical care they wish and supports the goals of hospice care.

Where do we as ministers fit in with hospice care? Even in hospice, we are still ministers for this member. Hospice organizations will have a minister or chaplain assigned to the member's case as well. The member has the right to refuse this service if they wish, however the hospice chaplain has a wealth of knowledge and experience in dealing with patients near death, and most would be more than happy to communicate and coordinate with you in the spiritual care of your member. We encourage you to reach out and connect with the Hospice chaplain, as long as the member agrees. This collaboration can be an invaluable resource and comfort to the member, but is a place where we need to make an effort. Remember though, you need to discuss this with the member first and get their permission to contact the hospice organization and their chaplain before doing so.

Scenario 4: Stopping Care

You do a home visit to a 36-year-old sister in the congregation. She was diagnosed with advanced breast cancer about two years ago. Since that time, she has had bilateral mastectomies and has gone through two separate rounds of chemotherapy, with the cancer returning each time within a few months of stopping treatment. She has been divorced now for the last 7 years and, due to her illness, she and her two children have had to live with her parents for the last 14 months. Her parents have been caring for both her and her children.

One month ago, a routine x-ray examination showed that the cancer had come back, this time in her liver and her pelvis. The doctors offered a different form of chemotherapy, but warned her that the odds of success were very low. She started the chemo, but after two rounds, has had a lot of trouble tolerating it. She has continued to lose weight, has become very weak, and is starting to appear like skin and bones. She has lost her hair and, due to the chemo medication, is suffering with constant nausea and vomiting that is making it difficult to keep anything down. She is unable to stand without two people helping her.

She tells you the first two times she took chemo were very rough on her and she decided to try this third one in an attempt to live on for her children. But, this particular one is worse than the first two combined and she doesn't think she can go on with it. She is miserable and in pain all the time. She feels that continuing to fight the cancer full-force is only extending her pain and the pain of her children, as they can only watch her get sicker and sicker. She hurts so bad from the medication that she can barely stand for them to hug her anymore. She wants to stop all further chemo and medications, except for those that control her pain and other symptoms. She asks if it is a sin to give up fighting the cancer, particularly since it looks like it will take her soon anyway. What do you tell her about that? Is it okay to stop treatments like this if the person feels that the benefits do not outweigh the costs and side effects?

Discussion:

This case is similar to the last scenario, but in this case, the member was started on a treatment in an attempt to prolong her life, but now has found the cost to be too high for too little gain. Based on personal autonomy, she has the right to stop a treatment even if it has already begun. This is called **WITHDRAWING** treatment. Ethically, there is no difference between withholding and withdrawing treatment, as long as it reflects that person's values.

Once again, it is acceptable and is not considered suicide or a sin to not pursue further treatment, as the person is allowing the natural processes to bring about their death and she is not actively causing it. In cases like this, where the condition is obviously terminal with death soon approaching, from either the cancer or the treatment itself, it could very reasonably be considered as accepting God's will. We cannot judge what lies in another's heart and have to, as ministers, accept the member's explanations and decisions at face value as valid.

The moral principle of personal autonomy is prefaced on the person being of sound mind and able to make clear, reasonable decisions. The exception to this occurs when someone is unable

to make clear, rational decisions for themselves due to either medical or psychological illness. Examples of this would be:

- a person with advanced dementia refusing pills because they don't understand what is happening
- someone with severe Schizophrenia or depression who is not taking their medications, or
- someone who has attempted to commit suicide but left instructions in some form that they are not to be revived or treated if found

However, these determinations are not for us as ministers to make, but must be left to the judgement of experienced medical professionals. All we can do in these situations is to support the member with love, compassion, and prayers.

Scenario 5: Withdrawal of Care for Another

In your congregation, there's an 83-year-old matriarch of an extended family. She has been in failing health for years and had to be placed in a nursing home about two years ago. You have been visiting her for pastoral care and to provide Holy Communion every few weeks since then, and have noticed a decline each time. She spends most of her time in either a wheel chair or the bed. She is progressively less conversational each time you visit, until the last time when she barely acknowledged you were there. She now needs to be fed if she is to eat and has to wear an adult diapers.

Three days ago, she was taken emergently to the hospital for new breathing problems. She was found to have a bad pneumonia and antibiotics were started. She continued to decline and was moved to the intensive care unit. Twenty-four hours ago, her heart stopped and they had to do CPR. The hospital staff were able to get her heart restarted, but now she is on a ventilator (life support machine), breathing through a tube. There are multiple wires running from her to monitoring equipment. She has a large IV line in her neck, through which they are giving fluids and medications in an attempt to keep her blood pressure up. A tube has been inserted into her nose to provide liquid nutrition. She also stopped making urine and the doctors say she is going into renal failure.

You are called by the family to see the patient in the hospital and to visit with them. You sit in the waiting room with the elderly sister's son and two of her three daughters. The third is en route from out of state. The doctors had come just before you arrived and explained that their mother is doing poorly and they do not expect her to survive this. The pneumonia is a treatable problem, but the damage done by her heart stopping and her poor health prior to this illness make it very unlikely that she will survive. While the medications and ventilator are keeping her alive for now, the chances of these treatments being effective enough to get her back to her previous state of health are very low. Even if they can get her through her current infection, they warned that she will likely come out of it permanently weaker and would likely require a permanent feeding tube in her stomach for nutrition. They said she might even need to have a long-term breathing tube in her neck if her breathing does not improve further. Also, with her kidneys not working, there is a high likelihood that she will need dialysis going forward, and that may mean she would need to go to a different nursing home, perhaps even outside the area, that supports this kind of advanced chronic care. The family asked the doctors if the dialysis and other care are considered futile. The doctors stated that while these interventions are not technically futile, they have a very low likelihood of truly healing her. The doctors have recommended the family consider making their mother a DNR (Do Not Resuscitate), which means if her heart stops again, they would not do any further CPR. In addition, they recommended taking their mother off the ventilator, stopping the IV drips, and removing the feeding tube in her nose to allow her to pass away in a more comfortable manner. They promised that no matter what the family decided, they would keep their mother as comfortable as they can.

The son and daughters are confused as to how to proceed. They all love their mother dearly, but are concerned that by stopping the ventilator and letting her go, they are giving up on her and possibly giving permission to kill her. They are divided: two children for withdrawing care and two for continuing with full heroic measures. The son and one daughter say they believe their mother

would not want to live like this or be stuck on machines keeping her alive. The other daughter and the one still traveling feel their mother is a fighter and would not want to give up, no matter what.

They ask you, “What should we do? Does the church support the idea of DNR? Does the church support withdrawal of care in circumstances like this? How do the doctors know she isn’t going to make it? Doesn’t the Lord only know when we are going to die? Are we killing our mother if we allow them to withdraw care? Are we starving her to death if we let them take out her feeding tube? How do we decide what to do?”

Discussion:

This elderly sister is in a very dire medical situation. She has been in poor health and now has most of her major organ systems shutting down. Commonly in this situation, aggressive measures, like the ones she is receiving, can keep her alive for hours, days, and maybe even weeks, but in the end will not likely heal her. So, the medical recommendation is to withdraw the aggressive medical care she is receiving and allow her to die, so she will not suffer needlessly. However, this is a moral and ethical decision, in addition to a medical one. There are several issues at play here.

Patient autonomy dictates that the patient has the right to decide what is in their personal and medical best interest. But who decides in cases like this when the patient cannot speak for themselves?

The decision falls to surrogate decision-makers. A surrogate is normally a family member that speaks on behalf of the patient. From a legal standpoint, this is usually someone the patient has previously designated, such as a healthcare power of attorney. If no such document exists, the surrogate decision-maker follows this pattern in most states:

- For a child, the parents become the surrogate decision-maker. If they are not available, then the grandparents.

- For an adult, the spouse becomes the surrogate decision-maker. If the person is unmarried or if the spouse is unavailable, then it falls to the adult children, followed by the person’s parents, followed by their siblings.

A very important thing we need to counsel our members on is that if they are the surrogate decision-maker for a person, they need to speak with the voice of the person for whom they are the surrogate. That means they should consider the situation or questions from the standpoint of what the patient would want if they were fully able to be there, hearing the information, understanding it, and speaking for themselves, not what the surrogate would want or do personally.

For example, in the above scenario, the children may find it hard to bear letting their mother go, but if she had previously told them that she did not want to live on mechanical means, then the answer is to let her go. The surrogate has to put aside their own wants and needs in the

situation and speak purely to the wants and needs of the patient.

What may help you here is a useful tool called Fierro's Four R's which helps you get into the mindset of the loved one, so that you can make the decisions they would want

1. **Reflect:**
   Think back and imagine (your loved one) when he or she was still able to make his or her own decisions.

2. **Reconstruct preferences:**
   Answer the following questions: What are his or her favorite things? What is his or her favorite color? What are his or her hobbies? What is his or her favorite meal? What things did he or she dislike?

3. **Now use that to reconstruct his or her values:**
   Think about whom he or she was, his or her opinions, his or her beliefs. What were his or her values? How did he or she choose to live his or her life?

4. **Review medical options and decide:**
   Now, imagine that (your loved one) is standing here beside you, looking at himself or herself here in this hospital bed. He or she hears the diagnosis and the available options the doctor has given. What does he or she want us to do, or not do next?

If you can get into the right mindset of the loved one, you'll make the decision they would want.

A DNR or do not resuscitate order can be in one of two forms: a document previously signed by the patient, similar to or part of a living will, or, as in this case, it can be an order placed by a physician, with either the patient's or family's approval, that instructs the staff to not do CPR or place a patient on a ventilator, should their heart or breathing stop. It is not an order to stop care for a patient, and all other orders and supportive care continue as normal. It just designates a line in the sand indicating that the patient does not want these heroics measures and that is the point where further escalation of care stops. A Do not Intubate (DNI) order is a variation that states a patient does not want to be put on mechanical ventilation, but would want cardiac resuscitation with CPR, cardiac medications, and/or electrical shocks.

Besides things like mechanical ventilation and CPR, nutrition via a tube and hydration via IVs can be considered heroic measures. Legal and ethical standards state it is acceptable for a patient to forgo either and this is purely a choice for the patient or family. They are considered life-sustaining measures, not comfort measures. For most patients that have entered an active dying phase, they lose their appetite and are not hungry. Filling their stomachs via the tube or putting fluids into their veins will not change that. In addition to that, these interventions can deprive a person of any pleasure that comes from eating, as this is all found in the oral phases of eating. They may also add pain and discomfort, as the feeding tube or IVs need to be inserted and maintained.

The church supports a DNR decision and the decision for forgo any life sustaining measures as

it follows the principals of patient autonomy and free will.

How do the doctors know when a patient is going to die? Medical science has progressed to the point that in certain situations, the approximate time of physical death can be predicted with some accuracy. The most likely outcome, be it life or death, can be predicted with a relatively good degree of accuracy. This is all based on what happens in a population of patients with the same disease. Examples: In 100 people with this condition, 80% will die from it, so that means 20 people will live through it. Or, a terminal disease with an average life expectancy of 6 months means that half of the people will live less than 6 months and half will live more than 6 months, with most of the deaths clustering around that 6-month range.

While there are signs and clues that can alert us that death is approaching, we can never predict the exact time or moment. This falls fully under God's purview.

What is futile care? The term futile care has undergone an evolution over the last several years. Traditionally, a physician has labeled care futile if the chances of the care fixing the problem are extremely low. In our example here, given the very low likelihood that even with continued blood pressure supporting medications, mechanical ventilation, and dialysis that this sister will recover to her previous state of health, all these interventions would have been traditionally considered futile at this point. However, Current medical literature has changed our definition of futile. It should now only be used to describe a course of treatment that has absolutely no chance of achieving the desired outcome. So once again, in our example, since dialysis, ventilation, and the other interventions still have a small chance of working (even if it is exceeding small), then they are not futile. An example of futile care would be giving a patient having a heart attack a medication to treat fungal infections. Fungal infections are in no way associated with the causes of heart attacks, so there is no chance that these medications would treat a heart attack. So anti-fungal medications would be futile care in the presence of a heart attack.

After all of this, how do we counsel this family?

At its basis, it would not be against our faith nor be considered a sin to withdraw this sister from life support and let her go. But, there are other issues here as well, mainly the division of opinion between the children, with two for withdrawal and two against. How do we proceed? How do they make a decision?

The correct decision can be arrived at through:

- Fervent prayers to the Lord by you and them to provide them with the spiritual wisdom to see His will and make the right decision.

- Frank and open discussion between the siblings until they can come together around a consensus on what the right course of action is going forward.

This may take some time to arrive at, if the Lord allows the sister to be stable that long.

In this situation, it is likely best not to make the decision, if possible, before the last sibling can

arrive and be fully a part of the conversations.

Reassure the children that if they earnestly pray and openly discuss the situation together, then they will arrive at the right decision on what to do, no matter what they decide.

These are things that may be appropriate to remind the siblings of:

- They need to make their decision in the best interest of their mother, not their own. They need to imagine what she would want them to do in this situation

- Sometimes, it is a greater act of love to let a loved one go than to keep them trapped in a painful, physical position. In the book “It’s OK to Die:, Monica Williams-Murphy and Kristian Murphy write, “Loving someone does not obligate you to use every medical intervention available to prolong their life. In fact, deeply caring for someone can mean that you should help to make them comfortable - and let them go.”

If it is not their mother’s time, then she will live despite any decision or action they may take.

Before moving forward on a decision, they need to find peace together around whatever they decide because even after her death, the family goes on and you don’t want it to be destroyed by these decisions.

As long as the mother’s condition is relatively stable, they need to take their time coming to a decision, but they cannot take forever. The answer should usually be arrived at within about 24 hours or so.

I will add, as a physician, given this scenario, what I would most like to see take place for this patient is that the children initially, and somewhat quickly, decide to make her a DNR. That way, I could continue her care, but not put her through further CPR and last-ditch heroic measures, when I feel in my professional opinion they will not likely help her. And then, over the next several hours and days, the family could come to an agreed upon decision, probably to withdraw care and let this sister transition to eternity’s realms.

The role of the minister is to encourage, support through prayer and be a sounding board to the family. But recognize we are not the decision-makers here. That lies with the family.

Scenario 6: Physician-Assisted Suicide

A 52-year-old active brother in the congregation asks to speak with you in the sacristy one day after service. While not ordained, this brother is a backbone in the congregation. He stands at the door and never fails to greet everyone with a smile and hearty welcome. He regularly mows the grass and handles many of the maintenance duties around the church, as he is a successful self-employed handyman. In addition, he is always willing to help with every congregational event and activity. He is married, but has no children. He and his wife are avid bikers, taking long rides every week and making treks to do scenic rides throughout the country.

Once in the sacristy, he reminds you that he was diagnosed 6 months ago with ALS, also known as Lou Gehrig's Disease, which is a progressive disease of the nervous system that will eventually leave him bed-bound, unable to stand, talk, eat, and eventually breathe on his own. The symptoms have been mild and not really limiting, until recently. He is starting to notice it affects his life more significantly and feels he cannot cope with the disability that is rapidly approaching. He is determined not to be a burden on his wife and says, "I will not go out as an invalid trapped on a machine."

He has been reading about physician-assisted suicide and is considering, once the disease progresses to a certain point, traveling to Oregon so that, with the help of a physician there, he can, as he says, "go out on his terms." Before he makes any decisions though, he is asking what the church's position is on physician-assisted suicide because in the end, he does not want to do anything against his Lord and faith. What is the church's position on physician-assisted suicide? Consider how you would respond to this brother.

Discussion:

We can all feel for this brother. He is in a difficult situation, the medical equivalent of being chained down to railroad tracks with no hopes of escaping, all the while hearing and seeing the oncoming train far in the distance.

Physician-assisted suicide is when a patient attains a prescription from a physician and that physician knows the patient intends to use it to commit suicide or actively end their life. Most medical doctors do not view this as ethical, but at this time it is legal in some states, including Oregon, Washington, Vermont, and Montana.

Unlike the other scenarios we have gone through, where care is being withdrawn or withheld to allow natural processes to cause the patient's death, this is an active intervention on the person's part to proactively end their life before they suffer the worst symptoms of their disease. Since this is a form of killing, the church views this as a sin and does not support it.

So what do we tell this brother? We need to encourage him to look and see what else the Lord may still have planned for his life. Is it possible he still has much to contribute? To take one's own life is a sin, no matter what the circumstance. We need to leave this to the Lord. Remind him that his symptoms could be controlled and alleviated with medications, and he can absolutely choose not to go on a ventilator. It could be very appropriate to create a living will and

make himself a do not resuscitate. All of these options would be in line with our faith and our ethics, while still avoiding much of the suffering he fears ahead. Encourage him to speak with his physician about all of this as well.

Let's contrast at this time the idea of euthanasia or physician-assisted suicide versus something known as "double effect." The purposeful delivery of enough medication either by a medical practitioner (euthanasia) or the patient themselves (physician-assisted suicide) in an effort to end that patient's life is considered sinful and unethical according to our doctrine. The practice of euthanasia is illegal in the USA. Both euthanasia and physician-assisted suicide are not supported by our faith.

However, the same medications that can be used in these ways are also used to relieve pain and suffering (i.e. narcotics, benzodiazepams).

So can we use these medications in patients, particularly at high doses, to relieve their suffering, knowing they could hasten a patient's death?

The answer is yes. The difference is in the intention behind giving the medication. This is called "double effect," which states that it is permissible to administer treatments if the intended effect is to treat symptoms, even if hastened death is a foreseeable, but unintended consequence. An example would be the administration of high dose narcotics to relieve pain in a terminally ill cancer patient, even if these doses could potentially hasten the patient's death. The intent here is to relieve suffering and control pain. The unintended consequence is to hasten death. However, the intended effect, pain relief, is not achieved through the bad effect, causing death.

Other parts of the world and societies may view euthanasia and physician-assisted suicide differently. Whatever the societal and legal circumstances, the doctrine of our faith is globally valid.

**Please not that the term "euthanasia" has different cultural and language connotations associated with it. Giving the negative connotations of euthanasia in the United States, the term has not been used in our teaching materials.*

Closing Content

As we close out this course, let's review:

- The church supports the rights of its members to make decisions in relation to their medical care at the end of life.
- The church supports withholding or the withdrawal of care if this is in line with the patient's wishes, and this includes living wills and DNR orders.
- The church does not support euthanasia or physician-assisted suicide.
- As ministers, we must remember situations surrounding the death of a loved one can be very stressful on the member and the family. We must strive to be a support for the member and the family, and offer our prayers on their behalf.
- Lastly, as ministers, we should be very careful to never inject our own personal opinions in what can be an intensely personal family matter. But, your role can be crucial in providing soul care for everyone involved in caring for loved ones at the end of life.

Resources

New Apostolic Church International Resource:

- Statements on Euthanasia and Palliative Care (available on Minister Companion)

Other Resources:

- *It's OK to Die* - Monica Williams Murphy and Kristian Murphy
- Ethical issues in end-of-life care. Hinshaw DB.J Med Liban. 2008 Apr-Jun;56(2):122-8.
- Ethical issues in palliative care. Erik K Fromme and Mary Denise Smith. UptoDate.com
- *Spirituality in Palliative Care: why, how, when and what* - Harold Koenig
- *Making Health Care Whole* - Christina M. Puchalski
- *Spirituality and End of Life Care* - Hospice Foundation of America
- *Death and Grief: A Guide for Clergy* - Alan Wolfelt
- *More Than a Parting Prayer: Lessons in Care-giving for the Dying* - William Griffith
- *Handbook for Chaplains: Comfort My People* - Mary Toole
- *The Indispensable Guide to Pastoral Care* - Sharyl Peterson
- www.healthcarechaplain.org - a variety of resources for ministers and chaplains

Latest statistics on CPR:

This page from AHA. Shows the rate of CPR given in the community along with survival to discharge from the hospital. Along with survival to discharge if it happens while a patient is admitted to the hospital. It also has the source paper available through the page as a PDF: http://cpr.heart.org/AHAECC/CPRAndECC/General/UCM_477263_Cardiac-Arrest-Statistics.jsp

Additional references about CPR:

https://mobile.nytimes.com/blogs/well/2014/07/17/the-cpr-we-dont-see-on-tv/?referer=

https://www.google.com/amp/s/amp.cnn.com/cnn/2013/07/10/health/cpr-lifesaving-stats/index.html

Appendix A

Fierro's Four R's
A Tool For Surrogate Medical Decision-Making

You, as the surrogate medical decision-maker, do not have to decide what to do by yourself.

Let (your loved one) decide for himself or herself, following these four steps:

1. **Reflect:**
   Think back and imagine (your loved one) when he or she was still able to make his or her own decisions.

2. **Reconstruct preferences:**
   Answer the following questions: What are his or her favorite things? What is his or her favorite color? What are his or her hobbies? What is his or her favorite meal? What things did he or she dislike?

3. **Reconstruct values:**
   Think about whom he or she was, his or her opinions, his or her beliefs. What were his or her values? How did he or she choose to live his or her life?

4. **Review medical options and decide:**
   Now, imagine that (your loved one) is standing here beside you, looking at himself or herself here in this hospital bed. He or she hears the diagnosis and the available options the doctor has given. What does he or she want us to do, or not do next?

Appendix B - Signs that death may be approaching

Signs that death may be months or weeks away

This suggested timeline is an average and may take place over longer or shorter periods of time. Only a few, or possibly all, of these things may occur.

- Increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (often exhausting family and caregivers)
- Withdrawal from active participation in social activities, personal interests, and hobbies
- Increased periods of sleep or developing lethargy
- Nausea, loss of interest in eating and drinking
- Changes in patterns of breathing
- Reports of seeing or talking to people who have already died
- Desire to finish “unsettled business” or to “tie up loose ends” with documents, friends, and family, possibly including passing along family treasures or heirlooms
- Increased frequency of illness with poor healing and recovery
- Increased swelling (edema) of extremities or entire body
- Statements suggesting that the person knows they are dying:
    - “This will probably be my last birthday.”
    - “Take this, I will not need it anymore.”
    - “Promise me that you will take care of my pet when I’m gone.”
    - “I know that I am dying.”

Signs that death is days or hours away (the active phase of dying)

This timeline and order of things may vary. Additionally, some people may appear to be in the active phase of dying, then “rally” and live hours or days longer than expected.

- The person may become less responsive and eventually enters a comatose state from which they are unable to be awakened.
- The person’s behavior may change drastically and become uncharacteristic. They may even become agitated and confused.
- Patterns of breathing become more irregular with progressively longer periods of no breathing at all (apnea).
- The sounds of fluid and congestion in the lungs become audible to those nearby (death rattle).
- The person may show an inability or refusal to eat, drink, or even swallow.
- The person may actually state that he or she is going to die.
- Bowel and urinary incontinence may occur.
- The jaw will fall open and breathing will occur through the open mouth.
- The person’s extremities will become cold to the touch and they may describe feelings of associated numbness.
- The body may become rigid and be held stiffly in position.
- Blood pressure will drop dramatically.
- Urine will turn dark, decrease in output, and then stop completely.
- Skin may turn pale or blue and purple (cyanosis), and a lacy, mottled type of “rash” may occur.
- Speaking will cease and the senses will turn off sequentially, but touch and hearing will be the last to go. This is why it is very important to speak to the dying and touch them to the very last.

From Hospice Patients Alliance- www.hospicepatients.org/hospic60.html