



Who is Your Advocate for Life and Death Decisions

by Fran Myers



Who is Your Advocate for Life and Death Decisions

by Fran Myers

When there is a person with dementia in the family, there needs to be special attention to many matters; Advance Directives is an important one. These directives provide guidance about the wishes of an individual who, for any reason, is unable to make their wishes known in a medical situation that requires a decision.

A fresh look at any Advance Directives you currently have will require renewed consideration around any existing wishes, as well as possible reassignment of roles. If you do not have any documents, now is the time to start.

The medical decision maker (formally known as a Healthcare Agent, Medical Power of Attorney or MDPOA) is the person to make the decisions about all matter of medical possibilities such as: tests and procedures, medications and surgery, life sustaining measures such as tube feeding and ventilation, and hospice.

Optimally in Advance Directives there is one primary agent, a secondary and a back up. Perhaps another person or two may need to be brought into the mix of Healthcare Agents in a family.

The person with dementia needs a primary and secondary agent at least. Anyone who had the person with dementia as their agent needs a replacement ASAP. That is often the case with a spouse or partner. If there are relatives, close friends or neighbors who are up to the task, they need to become familiar with your wishes and documents and the role of the healthcare agent.

The details of the Advance Directive for a person with dementia can be a bit different from those of the rest of the family. Careful decision making about the use of antibiotics for a urinary tract infection or pneumonia is an important one. While typically we treat such infections, many people elect not to treat those with advanced dementia with antibiotics. While keeping their loved ones comfortable, they allow the individual who is in a com-



Who is Your Advocate for Life and Death Decisions

by Fran Myers

promised medical state to pass away from the effects of the infection. This is a point to be considered in advance so that if that time comes, the question to treat or not to treat is not a shock.



An individual whose life is coming to an end often does not want to eat. In all cultures we want to feed one another as a sign of love and affection. Yet, there comes a time when feeding may become a problem. Often difficulty swallowing leads to aspiration pneumonia. The issue of hand feeding versus tube feeding is detailed in The American Geriatrics Society's recommendation for Tube feeding in Dementia (2-21-13):

“Do not recommend (percutaneous) feeding tubes in patients with advanced dementia; instead offer oral assisted feeds. Careful hand-feeding for patients with severe dementia is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Food is the preferred nutrient. Tube-feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.”

Refusing food and water is a natural, non-painful part of the dying process.

The decision regarding cardiopulmonary resuscitation matters. This bears decision making in “advance” so that if the time comes when there is no pulse or breathing, you and all caregivers know what the decision will be. The outcomes of Cardiopulmonary Resuscitation are dismal. About 1% of nursing home residents return to a normal life if they survive CPR. For most families, the choice is Do Not Resuscitate. It makes sense; any individual without a pulse or respirations is clinically dead.

The Do Not Resuscitate (DNR) decision is to allow and accept that moment of death to be the end. This decision should be honored. It is important to be prepared.



Who is Your Advocate for Life and Death Decisions

by Fran Myers

DNR is a physician's order always. It is not enough to decline CPR. The order must be in hand on a specific form signed by a physician. Speak to your physician about the DNR paperwork; if the physician agrees with the status you will get an order on a form. Make 5-10 copies. Copies are legal. All caregivers and family need to know the following:



- The status elected for the individual is:
- Do Not Resuscitate. NO CPR. Comfort Measures Only.
- The order from the physician should be visible on the refrigerator.
- It can also be above the patient's bed or on the door, depending on the circumstances.
- Know where it is. Do not hide it or file it away.
- Take a copy of the order with you if both leave the residence with the individual.
- Keep a copy of the order in the glove box.
- Have the form ready in hand for the rescue squad when they walk in the door if you call 911 or if you are in public or resuscitation will be started.

The reason for the above is that without an order, CPR will be started by the first responders if there is no pulse or breathing. It is the law. CPR is a very aggressive procedure. It is not often successful in the older patient and should not be done on anyone for whom a decision has been made to avoid it.

And, finally, even in moments of relative clarity, putting decision making squarely on the person with dementia is ill advised. That decision is being made from a smaller worldview than it should. If a person with dementia is interested and involved and wants to participate in making decisions, that is good. However, the healthcare agent must be willing to take responsibility for making decisions from an informed perspective, knowing that is their role promised medical state to pass away from the effects of the infection. This is a point to be considered in advance so that if that time comes, the question to treat or not to treat is not a shock.



Who is Your Advocate for Life and Death Decisions

by Fran Myers

An individual whose life is coming to an end often does not want to eat. In all cultures we want to feed one another as a sign of love and affection. Yet, there comes a time when feeding may become a problem. Often difficulty swallowing leads to aspiration pneumonia. The issue of hand feeding versus tube feeding is detailed in The American Geriatrics Society's recommendation for Tube feeding in Dementia (2-21-13): "Do not recommend (percutaneous) feeding tubes in patients with advanced dementia; instead offer oral assisted feeds. Careful hand-feeding for patients with severe dementia is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Food is the preferred nutrient. Tube-feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers."

Refusing food and water is a natural, non-painful part of the dying process.

The decision regarding cardiopulmonary resuscitation matters. This bears decision making in "advance" so that if the time comes when there is no pulse or breathing, you and all caregivers know what the decision will be. The outcomes of Cardiopulmonary Resuscitation

are dismal. About 1% of nursing home residents return to a normal life if they survive CPR. For most families, the choice is Do Not Resuscitate. It makes sense; any individual without a pulse or respirations is clinically dead.

The Do Not Resuscitate (DNR) decision is to allow and accept that moment of death to be the end. This decision should be honored. It is important to be prepared.

DNR is a physician's order always. It is not enough to decline CPR. The order must be in hand on a specific form signed by a physician. Speak to your physician about the DNR paperwork; if the physician agrees with the status you will get an order on a form. Make



Who is Your Advocate for Life and Death Decisions

by Fran Myers

5-10 copies. Copies are legal. All caregivers and family need to know the following:

Dependent Deductions

You may claim your parent as a dependent on your own income tax return if you meet five tests:

1. The status elected for the individual is.
2. Do Not Resuscitate. NO CPR. Comfort Measures Only.
3. The order from the physician should be visible on the refrigerator door, depending on the circumstances.
4. Know where it is. Do not hide it or file it away
5. Take a copy of the order with you if both leave the residence with the individual
6. Keep a copy of the order in the glove box
7. Have the form ready in hand for the rescue squad when they walk in the door if you call 911 or if you are in public or resuscitation will be started.

The reason for the above is that without an order, CPR will be started by the first responders if there is no pulse or breathing. It is the law. CPR is a very aggressive procedure. It is not often successful in the older patient and should not be done on anyone for whom a decision has been made to avoid it.

And, finally, even in moments of relative clarity, putting decision making squarely on the person with dementia is ill advised. That decision is being made from a smaller worldview than it should. If a person with dementia is interested and involved and wants to participate in making decisions, that is good. However, the healthcare agent must be willing to take responsibility for making decisions from an informed perspective, knowing that is their role.

For any questions please reach out to Fran Myers at Advance Care Advocate. Advance Care Advocate prepares Advance Directives through careful advance care planning. They also act as MDPOA Healthcare Agent for those who do not have an individual to take on that role.

