Describe ethical issues related to advance directives

1. UNDERSTAND THE NEED FOR ADVANCE DIRECTIVES
   1. Seminal case
      1. Cruzan v. Director, Missouri Department of Health
      2. References:
         1. Dowbiggin, I. (2013). From Sander to Schiavo: Morality, Partisan Politics, and America’s Culture War over Euthanasia, 1950–2010. Journal of Policy History,25(01), 12-41.
         2. <http://www.che.org/members/ethics/docs/2146/The%20case%20of%20Nancy%20Cruzan%20AC%20Module%2012.pdf>
   2. Why is there a need for Advance Directives?
      1. All hospitals and other health care institutions must inform patients of their right to agree to or refuse medical treatment. In addition, patients must be asked if they have an advance directive. If you are 18 or older and mentally competent, you have the right to make decisions about your medical treatment. If you want to control decisions about your health care, even if you become unable to make or to express them yourself, you will need an advance directive.
      2. References:
         1. <http://www.unchealthcare.org/site/healthpatientcare/patient/ethics/advance.htm>
2. UNDERSTAND THE TYPES OF ADVANCED DIRECTIVES
   1. What are Advance Directives?
      1. An advance directive is a form you sign now to direct your future health care if you cannot speak for yourself in the future. "Advance" means you tell your wishes ahead of time before you are too sick to talk. "Directives" means you direct your future health care. In this form, you state your wishes about what happens to you when you are dying or are in a coma and unable to speak. You decide if you want artificial treatments, which may keep you alive for a very long time.
         1. References:
            1. DIRECTIVES, A. (2000). Advance Directives for End-of-Life Medical Decisions. JAMA, 283(11).
            2. <http://www.unchealthcare.org/site/healthpatientcare/patient/ethics/advance.htm>
   2. Important laws and documentations:
      1. Reference:
         1. http://occupational-therapy.advanceweb.com/Article/Advance-Directives-6.aspx
      2. Patient self-determination Act
         1. Congress passed the Patient Self Determination Act (PSDA), which became effective in 1991. The act requires all health-care institutions that receive Medicare or Medicaid funds to provide patients with written information about their right under state law to execute advance directives, but it does not require states to adopt or change any substantive laws. The written information must clearly state the institution's policies on withholding or withdrawing life-sustaining treatment.
         2. References:
            1. <https://www.scu.edu/ethics/publications/iie/v8n1/advancedirectives.html>
      3. Living Will
         1. A living will is a document that tells others that you want to die a natural death if you are terminally and incurably sick or in a persistent vegetative state from which you will not recover. In a living will, you can tell your doctor not to use heroic treatment that would delay your death. You can also direct your doctor not to begin or to stop giving you food and water through a tube.
         2. References:
            1. <http://www.unchealthcare.org/site/healthpatientcare/patient/ethics/advance.htm/livingwill.html>
      4. Health Care Power of Attorney (also known as Durable Power of Attorney for Health care, Health Care Proxy, or Medical Power of Attorney
         1. A patient can name a person to make medical care decisions for you if you later become unable to decide yourself. In this legal document, you name who you want your "health care agent" to be. You can state what treatments you would want and not want so your agent will know what choices you would make. Both a living will and a health care power of attorney must be signed by you while you are still able to understand your condition and treatment choices and to make those choices known. A physician, nurse, social worker, chaplain, or patient relations representative can help you fill out the forms. They must be witnessed by two qualified people and be notarized.
         2. References:
            1. <http://www.unchealthcare.org/site/healthpatientcare/patient/ethics/advance.htm/poa.htm>
      5. Legal guardianship
         1. The purpose of a guardianship, which is governed by state law, is to protect the person and property of an incapacitated individual.
         2. References:
            1. <http://occupational-therapy.advanceweb.com/Article/Advance-Directives-6.aspx>
      6. Physician orders for life-sustaining treatment (POLST)
         1. A POLST is a prescriptive instruction to Emergency Medical Services and your health care team that communicates your wishes related to resuscitation.
         2. References:
            1. <https://www.whidbeygen.org/my-hospital/advance-directives/why-are-advance-directives-important>
      7. Do not resuscitate (DNR)
         1. Request by the patient to not receive cardiopulmonary resuscitation in the event his or her heart stops or he or she stops breathing while at the hospital
         2. References:
            1. Santonocito, C., Ristagno, G., Gullo, A., & Weil, M. H. (2013). Do-not-resuscitate order: a view throughout the world. *Journal of critical care*, *28*(1), 14-21.
            2. <http://samples.jbpub.com/9781449634476/80593_ch25_5806.pdf>
   3. Where can a patient find the above documents?
      1. US Living will registry: <http://uslwr.com/formslist.shtm>
3. ADDITIONAL RESOURCES
   1. Myths and facts about Health Care Advance Directives: <http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_bk_myths_factshcad.authcheckdam.pdf>
   2. Literature review on Advance Directives: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>
4. RELEVANCE TO OCCUPATIONAL THERAPIST
   1. Common scenarios
      1. Pt’s family is requesting DNR but patient is not.
      2. When it is obvious that a patient’s condition is grave and terminal and the family insists upon CPR or therapy.
      3. Prolonging life would be cruel and unfair without thought on the quality of life.
      4. Pt codes (not DNR) CPR and advanced life support started. Sister arrives during code and states she wants CPR stopped—states she is her guardian (nothing in chart).
      5. Sister states she has cared for patient for 10 years in her home.
      6. DNR status with outpatients.
   2. References:
      1. Kirschner, K. L., Stocking, C., Wagner, L. B., Foye, S. J., & Siegler, M. (2001). Ethical issues identified by rehabilitation clinicians. Archives of physical medicine and rehabilitation, 82, S2-S8.
5. SAMPLE CASE #1
   1. Reference: <http://ncsu.edu/ffci/publications/2003/v8-n1-2003-january/editors-corner.php>
   2. Case: A recent case in North Carolina addresses the issue of whether survivors must honor the wishes of a patient who does not want life support. The case is currently at the trial level, however, and the issue must be appealed to a higher court before we have a definitive answer. The case involves a 27 year-old woman, Tina, who is in a vegetative state as a result of complications following surgery. Before surgery, Tina had signed a living will indicating that she did not want to be kept on life support systems under these circumstances. Her parents are suing the hospital for malpractice and asking for $48 million for their daughter's pain and suffering and for ongoing medical expenses over her projected life span of 50 more years. The hospital moved to dismiss the request for $48 million, arguing that Tina's parents are overriding her desires and demanding life support so they can make more money from their lawsuit against the hospital. The trial judge ruled, without elaboration, that the hospital is not liable for the estimated $48 million in special damages. This issue is subject to appeal, but the underlying malpractice lawsuit is not affected by this ruling. If the issue is appealed to a higher court, lawyers, medical providers, and interested citizens will be awaiting the outcome with keen interest. The case has the potential of answering at least some of the legal and ethical questions surrounding advance directives and end-of-life issues that have been debated in North Carolina for years. What issues will be addressed, if any, may prove as interesting as the outcome.
   3. Questions Some of the potential legal/ethical issues that may arise include:
      1. What is the role of the family in end-of-life decisions?
      2. What is the role of advance directives in rationing health care as resources dwindle?
      3. What constitutes a living will?
      4. Should a living will be mandatory?
      5. If there is a conflict between a living will and health care power of attorney, which document should control?
   4. Possible answers: <http://ncsu.edu/ffci/publications/2003/v8-n1-2003-january/editors-corner.php>
6. SAMPLE CASE #2
   1. Reference: https://depts.washington.edu/bioethx/topics/advdirc1.html
   2. Scenario: An elderly man with end-stage emphysema presents to the emergency room awake and alert and complaining of shortness of breath. An evaluation reveals that he has pneumonia. His condition deteriorates in the emergency room and he has impending respiratory failure, though he remains awake and alert. A copy of a signed and witnessed living will is in his chart stipulates that he wants no "invasive" medical procedures that would "serve only to prolong my death." No surrogate decision maker is available.
   3. Questions: Should mechanical ventilation be instituted?
   4. Possible answers: If the patient has remained awake and alert, his living will is irrelevant to medical decision making. The potential risks and benefits of mechanical ventilation need to be presented to the patient. If he refuses this therapy with an understanding of the consequences, his wishes should be honored. If he opts for mechanical ventilation, it should be instituted when it becomes medically necessary. The presence of a living will or other advance directive does not obviate the responsibility to involve a competent patient in medical decision making.
7. SAMPLE CASE #3
   1. Reference: <https://depts.washington.edu/bioethx/topics/advdirc2.html>
   2. Scenario: The same patient described in Case 2 presents confused and somnolent.
   3. Question: Should mechanical ventilation be instituted?
   4. Possible answers: f the man has deteriorated to the point that he can no longer communicate, his living will may be a helpful guide to decision-making. The language of the directive, however, is difficult to interpret in this case. Pneumonia represents a potentially reversible condition from which the patient may recover fully. Mechanical ventilation does not serve only to "prolong death" but offers a significant chance to return to his previous level of functioning. Most patients with even end-stage emphysema can be successfully weaned from mechanical ventilation. The intent of the directive, whether to avoid intubation and ventilation at all costs or simply to withhold such therapies when they are clearly futile, is not evident. In the absence of other information to aid the decision, mechanical ventilation should be instituted, with the plan that it be discontinued if it becomes evident that the patient cannot be weaned.