



ORIENTATION SEED PACKET #5 - - END of LIFE DECISIONS

Enclosed is Orientation SEED Packet #5 which includes articles and excerpts on some very tough topics - - Advance Directives, Do Not Resuscitate Orders, and Organ Donation. Be aware that these are presented subjectively and do not specifically reflect Firely Pediatric Service's opinion regarding these topics. Additionally, FPS Policies are referenced for your use as needed. Please read through the packet, take the post-test, and return the post-test only to the Main Office.

Thanks so much!

Susan Dee Mellett, RN

Assistant Administrator, SEED Director

END of LIFE DECISIONS

No one should have to make such tough decisions. Unfortunately many of us already have or will have to do just that. Even worse is making these decisions for a child. As one can imagine, stress levels have been measured as extremely high for family members who must decide whether or not life support should be withdrawn from relatives too incapacitated to decide for themselves. Researchers from the Oregon Health Sciences University conducted a study published by the National Institutes of Health (NIH) which will be referred to throughout this packet. They reported levels of stress are twice as high as those due to other serious crises such as losing a home in a fire. Stress was less severe when patients' written advance directives were available, and most severe in the absence of written or verbal directives.

Regardless of the stress level, parents should be informed of their options regarding any serious illness of their child. All FPS health care workers should encourage parents to discuss their questions, fears, and preferences with their child's physician, as well as the family's religious leader(s), if available. If this is not done, parents could face an urgent situation that is far more emotional and far less rational than being well-informed and prepared ahead of time. Virginia Tilden, DNSc, RN, the principle investigator in the study, stated "With advance directives, families are able to concentrate on improving the patient's quality of life during the time left, rather than futilely prolonging life, with high risk of making patients suffer unnecessarily."

Susan Tolle, MD, a co-investigator of the study, indicated that "nurses and doctors can play a strong role in encouraging patients before they become gravely ill to complete advance directives and to discuss them with their families. This will reduce stress on their families down the road."

ADVANCE DIRECTIVES

Advance Directives are oral/written instructions regarding medical care preferences. Any competent individual age eighteen or older may prepare an advance directive for him/herself. Parents are legally able to prepare an advance directive for all minor children {up to and including age seventeen} and incompetent children age eighteen years or older.

Advance directives usually take one of two forms:

- Living Will ~ A written, legal document that spells out the types of medical treatments and life-sustaining measures desired or not desired, such as mechanical respiration, tube feeding, etc. This is also referred to as health care declaration or health care directive.
- Medical Power of Attorney {POA} ~ A legal document designating an individual to make medical decisions on behalf of the patient in the event he/she is unable to do so. The Medical POA is different that the POA who has been authorized to make financial transactions for the patient. The same person, or two different people, can be named for both "positions." Some people are willing to make health care decisions but not financial decisions; likewise, the opposite may be true. The Medical POA is also referred to as a Durable Power of Attorney for health care.

CHOOSING ONE who'll CHOOSE for YOU

Unless an individual is formally appointed to make decisions for another, health care providers and institutions will make critical decisions that might not be based on the patient's wishes. In some situations, a court may have to appoint a guardian unless an advance directive is in place. Therefore, choosing a Medical POA is possibly the most important aspect.

It is very important to look at the qualities and values of each "candidate" for designating a medical POA. Special consideration should be given to:

- Avoid choosing one person because of feelings of guilt or obligation
- Qualities of being level-headed, mature, able to remain calm in a crisis, etc.
- Religious beliefs that do not conflict with the patient's beliefs
- Most importantly, one that is able to fully understand the medical aspect of a variety of situations, and be trusted to carry out pre-stated wishes.

WHAT to CONSIDER

There are at least four important questions to ask:

1 ~ What are the goals for medical treatment?

What should the treatment{s} accomplish ~ prolong life no matter what or, if life-sustaining treatment could not restore consciousness or an ability to communicate, end treatment{s}? Once goals have been stated, health care workers or the Medical POA can make medical decisions based on the goals. If treatment would help achieve one or more goals, then it would be provided. If treatment would not help achieve at least one goal, then it would not be provided.

In formulating goals, it is often helpful to consider wishes about different end-of-life treatments, and why they are important, as well as examining values and attitudes.

2 ~ Who should be the Medical POA?

Choose one person to serve this position to avoid disagreements {two or more people could disagree, leaving health care workers unclear in their response}. It is possible to name an alternate agent to be utilized in the event the designated Medical POA is unavailable.

3 ~ How specific should the advance directive be?

Be aware that no advance directive can be completely sound, covering all medical situations that could possibly arise. See "Treatments to Consider" section below. It is advised that many aspects be discussed with the Medical POA to ensure the initial wishes, values, and preferences are respected.

4 ~ How can one be assured that the advance directive will be followed?

Health care providers may have personal views or values that do not agree with the stated conditions, rendering them unwilling to follow the advance directive. Most states allow health care providers to refuse to honor an advance directive on conscience grounds. However, they generally must find another health care provider who will honor the advance directive.

To avoid problems, the advance directive should be discussed with the health care provider ahead of time; if there are objections, they should be worked out or an alternate health care provider should be located. Also, a signed copy should be given to the health care provider, as well as the Medical POA.

TREATMENTS to CONSIDER

As stated above, there are an infinite number of scenarios that could occur. Additionally, would it matter if the prognosis was terminal, or if the condition was able to improve? Some of the basics are as follows:

- Resuscitation ~ Determine if and when CPR or defibrillation should occur.
- Mechanical Ventilation ~ Consider if, when, and for how long a ventilator would be used.
- Nutritional and Hydration Assistance ~ Decide if, when, and for how long the patient would be fed via enteral or parenteral nutrition/hydration.
- Hemodialysis ~ Determine if, when, and for how long to continue the treatment. Would it matter if the need for dialysis was temporary or permanent?
- End Stage Treatments ~ Includes antibiotics, pain medication, and mechanical ventilation. Would it be used as comfort measures if the prognosis was that it would only delay imminent death?
- Organ Donation ~ Examine personal preferences.

COMPLETING the FORMS

It is very important to put everything into writing according to state requirements. Once the forms have been filled out, copies should be given to the physician, Medical POA, alternate agent{s}, attorney, if designated, and family members. Periodically review the forms.

FPS POLICIES

All patients have a basic right in receiving information about formulating an advance directive. Upon admission to FPS, the option of advance directives and DNR orders is discussed with each Client's family. If requested, written information is also provided to the family. Any resuscitation information that is placed in an advance directive / DNR Order is detailed in the Client's POC (485). In addition to the required physician signature, FPS requires the parents / guardians of the child to sign as well. The POC is updated at least every 62 days and requires new signatures, thus maintaining up-to-date information.

All nurses caring for FPS Clients have a two-fold requirement - - to educate the Client and Family regarding their right to formulate an advance directive and to support all aspects of a Client's advance directive/DNR Order. These represent a family's most personal values and must be respected. If, at any time, a nurse experiences conflicting views that prevent him/her from upholding all items in an advance directive, Administration {Case Coordinator, Program Director, Child Care Supervisor, etc.} must be contacted immediately.

Quick Reference Checklist:

- Determine values and wishes related to medical care
- Discuss wishes with family, friends, doctor, religious leader, attorney
- Appoint a primary and alternate health care agent to provide medical Power of Attorney
- Put everything in writing, filling out appropriate state forms
- Distribute completed forms to doctor, family and health care agents
- Review directives each year and communicate changes to those involved

WORKS CITED

- "Advance Directives: Make your medical care wishes known." MayoClinic.com. <<http://www.mayoclinic.com/invoke.cfm?id=HA00014>>.
- American Academy of Pediatrics. "Do-Not-Resuscitate Orders Need to be Reconsidered for Pediatric Patients who Require Anesthesia and Surgery." Pediatrics. 6 December 2004 <<http://www.aap.org/advocacy/releases/decdnr.htm>>.
- American Association of Retired Persons, the American Bar Association Commission on Legal Problems of the Elderly, and the American Medical Association. Shape Your Health Care Future with Health Care Advance Directives. 1995.
- Bensing, Kay, MA, RN. "End-of-Life Care." advance for Nurses. 4 April 2005.
- Cook, Linda & Newman, Jim. "NIH News Release." Advance Directives Found Key to Reducing Stress for Families of Hospitalized Patients at the End of Life. Thursday, March 15, 2001. <<http://nih.gov/news/pr/mar2001/ninr-15.htm>>.
- Dristiliaris, Tami M., JD, BSN, RN. "Advance Directives." advance Online Editions for Nurses. 23 March 2005.



ORIENTATION SEED PACKET #5

End of Life Decisions Post-Test

Name: _____

Date: ____ ~ ____ ~ ____

Circle the best answer:

- | | | |
|------|-------|--|
| True | False | 1. A Family's stress is generally less severe during an end-of-life situation when an advance directive is present. |
| True | False | 2. An advance directive usually takes one of two forms - - formulating a Living Will and designating a Medical Power of Attorney. |
| True | False | 3. A Living Will contains information about medical decisions and personal property. |
| True | False | 4. A Medical Power of Attorney is always the same person who will make decisions about the deceased's personal possessions. |
| True | False | 5. In some situations, a court may have to appoint a guardian if a Medical Power of Attorney has not been designated. |
| True | False | 6. In the process of formulating an advance directive, once goals are identified, the Medical POA and health care workers can make medical decisions better suited to the family's wishes. |
| True | False | 7. It may be best to designate just one person {rather than several people} as the Medical POA to avoid disagreements. |
| True | False | 8. Health care providers may have personal views or values that do not agree with the stated conditions in an advance directive. |
| True | False | 9. FPS does not provide information about advance directives to Clients and families. |
| True | False | 10. Advance directives involving FPS Clients are renewed once every six months. |
| True | False | 11. All nurses caring for FPS Clients are required to support all aspects of an advance directive/DNR Order as it reflects a family's most personal values. |
| True | False | 12. If a nurse experiences conflicting views that prevent him/her from upholding all items in an advance directive, he/she must inform Administration immediately. |