A Protocol for Medical Decision Making

Course level: Intermediate

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This module has been adapted from a presentation made at the National Guardianship Association’s 2006 Conference on Guardianship.

Course Objectives:
- The guardian will be introduced to a protocol for making health care decisions on behalf of a ward.
- The guardian will be able to apply the protocol to a hypothetical fact pattern.
- The guardian will understand the difference between making a decision based on substituted judgment and best interests.
- The guardian will understand the benefits of using a protocol in both solo practice and multiple practitioner settings.

Course References:
- National Guardianship Association Standards of Practice found at www.guardianship.org
Introduction

A protocol for medical decision making can be very useful to guardians in solo practice and as well as those who are in agencies. The purpose of the protocol is to provide order to decisions that encompass many variables that impinge on and confuse the issue simultaneously. With repeated use, a protocol allows us to order our thought processes, maintain our focus on the ward, prioritize benefits and risks, establish standard criteria, and maximize more predictable outcomes for wards.

The following protocol was developed using the National Guardianship Association Standa rds of Practice and Code of Ethics.

As surrogate decision-makers it often becomes incumbent upon us to make health care decisions for our wards. In many instances we are pressured to make these decisions instantly so that other professionals can get on with their jobs. Health care professionals, police, and social services agencies may be generally less concerned with the complexities of these decisions or their consequences. They may have already become committed to their own decision as to what they think is best. However, as the surrogate decision maker, you are responsible to make that decision within the historical life-style parameters of the ward or alternatively what is in the ward’s best interest. To do otherwise can leave the surrogate decision-maker open to liability.

Step One
The Decision Between Substituted Judgment or Best Interest

Using Substituted Judgment means that you will use the ward’s desires, philosophies, religious beliefs, past and current opinions and behaviors to determine what form of treatment the ward would chose for themselves. This standard for making a decision for another is ethically preferred, and in some instances, statutorily required.

Direct Knowledge of the Ward’s Choice

Can the ward participate in the decision making process? In many cases the ward can participate. Participation in this decision is dependent upon the ward’s ability to:

- understand language,
- understand the treatment,
- understand the outcome of the treatment,
- communicate descent or agreement with the treatment.
Many wards who suffer from mental illness, brain trauma injuries, developmental disabilities, infarction dementias, deliriums, and early stage Alzheimer’s disease are able to understand their circumstances, risks of treatment and outcome of treatment. Under these circumstances the desires of the ward should dictate the decision of the guardian. When family, health care providers or religious persons object to the ward’s choice, it is the guardian’s obligation to act as the ward’s advocate for the ward’s desires.

**Indirect Knowledge of the Ward's Choice**

Another method to guide the guardian’s decision-making process must be found when the ward is unable to participate in decision making due to an inability to retain and process information. At this point the guardian must use historical information to determine what the ward would have done if he or she were not cognitively impaired.

The surrogate decision-maker should look for guidance through:

- Any living will that states the patient’s health care preferences or other patient advocate documents when the patient advocate is no longer available to make the decision or provide guidance.
- Any Power of Attorney or Power of Attorney for Health Care.
- Interviews with family and friends.
- The guidance of the ward’s spiritual advisor.

There will be times when this guidance is not available or is inadequate. At these times the surrogate decision-maker must look to the Best Interest of the Ward to determine the best course of action.

### Step Two

**The Best Interest of the Ward**

At this time the surrogate decision-maker is no longer standing beside the ward and supporting their right to self-determination. Now the surrogate decision-maker must stand in the shoes of the ward and must chose between many alternatives. Through interviews with the family, community, and spiritual leaders you should have a well detailed picture of who this person is or wanted to be. You now stand for the ward’s best interest and not the interests of the family, community, health care professionals or clergy. The family, community, health care providers, and the clergy all have a role to play, but they may also have their own agendas and values to promote.

The following is a list of appropriate questions to ask with suggestions on how to flow through the maze of information needed to make your decision.
1. First and always, how’s my ward???
This may be the most important question that you ask. That’s why it is the first. Before you can enter any course of treatment for your ward you need to know exactly what is the ward’s physical and emotional condition. To determine this you may have to talk to more than one doctor, nurse or family member. However, your mission at the outset is to determine if your ward can tolerate the recommended treatment physically, emotionally, and socially. If not, there is no point to pursuing that particular treatment.

2. What are the alternative treatments for my ward?
There are always alternatives to the primary treatment that a health care professional suggests. Make sure you know what treatments are available. You may need to consult more than one health care provider, or possibly different disciplines. For example: Wilma has been seen by the doctor in the nursing home because she has developed a bunion on her right foot. The nursing home doctor recommended that she be seen by an orthopedic surgeon. The surgeon recommends surgery to remove the bunion. The podiatrist recommends that he remove the bunion by freezing the growth and allowing it to fall off. The nurse practitioner has been having Wilma soak her feet in a whirlpool daily and the growth has been consistently lost size. Wilma enjoys the whirlpool and the attention she gets from the nurse practitioner.

3. What is the least restrictive and least invasive treatment?
The surrogate decision-maker should list all treatments from least restrictive and least invasive to most restrictive, most invasive and most debilitating. The alternative treatments should be taken one at a time to determine the efficacy of the treatment.

4. Starting with the least restrictive and invasive treatment asks: Has the alternative treatment been tried with the ward and with what results?
a. If not, why not?
If the treatment will not harm the ward and has a probability of benefiting the ward, Go to 7

b. If it has been tried, was it vigorously pursued?
Example:
An elderly lady with dementia no longer remembers to feed herself at mealtimes and instead is fascinated by the people around her. The nursing home would like to send Mrs. Malo to the hospital to install a peg tube so they can feed her by machine and stop the weight loss. The guardian insists that they try encouraging her to eat and try feeding her when she is unable to do so. However, the staff is reluctant and haphazard about doing so. The guardian brings this to the attention of other families whose relatives must be hand fed and the family counsel. The involvement if the Family Counsel encourages the nursing staff to be more attentive to the nutritional needs of the residents.

No, go to 7 If Yes, go to 3 chose an alternative treatment
c. The alternative has been attempted and has failed. 
Repeat the process with the next least restrictive and least invasion treatment, starting at 3, until you find a treatment that has not been tried or has been tried in the past and worked for the ward.

If it worked, go to 7  If it didn’t work, go to 3

5. Can my ward accept this treatment? 
Once the least restrictive and least invasive treatment has been identified, it must be determined whether or not the treatment will be palatable to the ward.

a. Will my ward be able to participate in the recovery process? 
Many wards have cognitive or physical conditions that prevent them from participating in recovery and disable them further.

Example: 
Mr. Henry suffers from infarction dementia due to a stroke. He has difficulty following instructions to a third step.** Nevertheless, he lives with his daughter and enjoys an active family life with his two grandchildren. The doctor has recommended that Mr. Henry have a hip replacement surgery. It is probable that Mr. Henry will not be able to participate in the physical therapy necessary to recover from the surgery and may be confined to a wheelchair and/or a nursing home.

If no, go to 3.

b. Will the treatment restrict my ward’s lifestyle to the point that they become despondent?

Example: 
Mrs. Zerrelli suffers from severe Rheumatoid Arthritis. As a result she is wheelchair fast and has a severe heart condition. She has very little strength and cannot transfer herself. Even though she has been experiencing chest pain she strives to participate in the activities at the nursing home. She enjoys each day that she spends with her friends, and is more or less the instigator of all things fun at the nursing home. The doctor wants Mrs. Z to begin therapy with a corticoid steroid that may cause bruising, stomach bleeding, dizziness, and may even change her personality These side effects would restrict Mrs. Z’s participation in the social activities and her role as queen of the nursing home.

If yes, go to 3 with an emphasis on exploring new treatments and treatments that have worked in the past for Mrs. Z.

If no, go to 7.

** The term of first through fifth step is a term of art in social work and education that indicates the ability of an individual to perform tasks. For example; if you ask Mr. Henry to put on his shoes, his socks and go to breakfast, Mr. Henry will not remember; become overwhelmed; or too confused to get past putting his socks on.
c. Would my ward have religious or philosophical objections to this treatment?
Example:
Mr. Haddad is/was a practicing Moslem. He is suffering from stage 3 Alzheimer’s disease. Last night he burned himself when he fell into the barbeque grill at a family picnic. The doctor at the hospital wants to perform skin grafts using pig skin. The use of this treatment would violate the Moslem religious ban on any physical contact with a pig.

If yes, Go to 3 or explore other materials that can be used for the skin graft. The doctor finds that a graft can be made using small bits of skin from Mr. Haddad’s hip.

If no, go to 7.

6.a. What happens if we do nothing?
There are times when a delay in treatment may cause the treatment to become unnecessary. Other times immediate treatment must occur to sustain the ward’s level of functioning.

Example 1:
Mrs. Jason has multiple sclerosis. Recently her swallow reflex has been affected and she has had three episodes of choking. The doctor advises that this is part of the normal course of the disease, and that insertion of a peg tube for feeding will eliminate the problem. If a peg tube is not inserted there is the possibility that Mrs. Jason will aspirate some food and develop pneumonia. The Speech Therapist reports that she may be able to help Mrs. Jason retrain the muscles in her throat. There is also a 50% possibility, since this is a first episode, that Mrs. Jason will retrain her throat to swallow normally on her own.

Exercise #1. What would you do?

What are the treatment alternatives?

Order your alternatives from least restrictive / invasive to most restrictive / invasive.

Starting with the least restrictive and invasive treatment, ask for each: Has the alternative treatment been tried with the ward and with what results?
6.b. Why now and not later?

Example: Ms. Libenczeck suffers from paranoid schizophrenia. She is a chain smoker. Even though her social skills are marginal she enjoys attending a day treatment program at the local community health center. For the past two months the staff at the Adult Foster Care home has reported that she had been coughing excessively. Upon a visit to the doctor, he discovers that her color is very poor. Upon examination of her throat he finds that there is a large mass in her throat. Ms. Libenczeck is sent to an Ortholaryngologist who discovers that Ms. Libenczeck has a mass in her throat that only allows air to pass into her lungs through a tiny pin hole. There are courses of treatment that they can pursue but they must be pursued immediately to prevent stroke, or possible suffocation.

The first alternative suggested is to excise the tumor entirely. Due to its size the larynx and thyroid gland will have to be removed and there will be damage to the neck muscles.

Post surgery Ms. Libenczeck will breathe through a canula in her neck. She will be fed through a nasal gastric tube until her throat heals and the newly built vestibule to her stomach heels. Because she will not be able to take air in through her nose, she will no longer be able to smell. She will have speech therapy to learn to use a voice simulator. She will have physical therapy because she will need to retrain her neck muscles to hold her head up. She will need to take thyroid medication for the remainder of her life.

The second alternative suggested is to excise enough of the tumor to open the airway and analyze the excised sample to determine the type of the malignant cells. This procedure will leave a scar in Ms. Libenczeck’s neck. Masses of the size of Ms. Libenczeck’s have a 95% chance of being malignant. Depending on what type of cancer it is, it could begin to spread as soon as the surgery is performed. It is possible that Ms. Libenczeck will have to have the radical surgery a week later.

The third alternative suggested is a traceostomy to allow Ms. Libenczeck to breath. During this minor surgery a needle biopsy of the mass will be taken and cauterized to prevent any spread of malignant cells. The results of the needle biopsy will be available in a week. Due to the size of the mass there is a 95% chance that the tumor is malignant. However the type of tumor cell will determine any further course of action. In some cases, irradiation can be done before the tumor is excised. The irradiation shrinks the tumor so that less damage need be done to the surrounding tissue during excision of the tumor.

Exercise #2.
Taking each alternative, discuss the process that would be used to determine the guardian’s most immediate course of action.
7. At first glance this protocol seems to be a long and complicated process. However, because the least restrictive alternative is evaluated first, when the protocol is put into use it is rare that all the alternative treatments have to be analyzed. Furthermore, this thought process allows the surrogate decision-maker to be more confident in their judgment for their ward than if no protocol is used at all. If there is ever a question by the family, the community, or the court, the surrogate decision-maker will be ready to respond logically and with assurance.

Finally, there are some treatments that are so invasive and controversial that they are the treatments of last resort. These treatments include Electro-Convulsive Therapy [ECT], abortion and discontinuation of all therapies. When these situations arise it is recommended that the surrogate decision-maker consult with the hospital or public health departments Bio-Ethics Committee. Ultimately the surrogate-decision maker may need to consult with the court before proceeding with a controversial therapy.

You won’t be discredited for admitting that you are not sure. You can be discredited—and sued—if you cannot explain why and how you made a particular health care decision.