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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 *Standards 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 Ortholaryncologist 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.

Conclusion

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.

	Website Training TEST

A Protocol for Medical Decision Making

Test Information: A passing score is 75%. There are 100 possible points. Each question is worth 1 point unless another point value is assigned.

Payment of $50 for NGA members or $60 for non-members (Family or volunteer guardian fee is $25 for NGA member or $30 non-member) must accompany the test answers for scoring to occur. You will be notified of your test score within two weeks by email. If you receive a passing score, a certificate will also be emailed.

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Are you a member of the National Guardianship Association?	Yes	No
Are you certified through the Center for Guardianship Certification?	Yes	No
Would you like information about NGA membership?	Yes	No
Would you like information about becoming a National Certified Guardian?	Yes	No

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Please print your name at the top of each page: _____

Test Questions

Scenario One

Linda McKenzie is a fifty year old woman. She has suffered from Bi-Polar Disorder since the age of sixteen. Ms. McKenzie has been cycling through the symptoms of the disease more slowly in the past twelve years. During periods of mania she displays all the symptoms of a person with grandiose ideas experiencing mania. The manic slope of the cycle can last from two to six months and usually culminates in a mixed episode. During mixed episodes Ms. McKenzie is combative, rude, provocative, and extravagant. She has been arrested several times during her mixed episodes. Her mixed episodes usually end with a suicide attempt. Her severe depression with suicidal ideations often continues for four to five months. Her periods of balanced thought processes and stable mood have been lasting for five to six months.

Over the past forty years Ms. McKenzie's physicians have tried a wide range of pharmaceutical interventions. Several of the drugs have relieved her symptoms for two to seven months at a time. However, she has become inured to most of the drugs that are traditionally used for treating Bi-Polar Disorder. The depression that she is currently experiencing has been particularly deep and has now persisted for over seven months. During that time period she has made two suicide attempts and experienced four psychiatric hospitalizations. Her physicians have approached you with the possibility of treating Ms. McKenzie with ECT. You have had a good relationship with Ms. McKenzie and her family over the seven years that you have been guardian for her.

1. (6 points)
When considering treatment alternatives for Ms. McKenzie what standard of judgment should you be using?
___ a. Direct substituted judgment and indirect substituted judgment
___ b. Direct substituted judgment
___ c. Indirect substituted judgment
___ d. Substituted judgment

2. (8 points)
Before making a decision on treatment options for the ward, who would be most important to consult? Check all that apply.
___ a. Ms. McKenzie (the ward)
___ b. Family
___ c. Friends of the ward
___ d. Spiritual advisor
___ e. Living Wills
___ f. Invalid Patient Advocate
___ g. Patient Directive Forms
___ h. Nurse
___ i. Doctor/physician
___ j. Direct care staff

*Please print your name at the top of each page*_____

3. (Six points)
Indicate three of the most important questions that you should ask about the treatment alternatives that are available to Ms. McKenzie?
___ a. Is this the least invasive and least restrictive or debilitating treatment possible?
___ b. Has the treatment been tried before and with what results?
___ c. Can the ward tolerate the treatment physically?
___ d. Can the ward tolerate the treatment socially?
___ e. Can the ward tolerate the treatment ethically or religiously?
___ f. What would happen if we did nothing?
___ g. Why use this treatment now and not later?
___ h. What are the short-term side effects?
___ i. What are the long-term side effects?
___ j. How long can the benefits of the treatment last without return of symptoms?
___ k. What is the recovery time for the treatment?
___ l. Will some therapy be necessary to prevent debilitation after the treatment?

4. (6 points)
Who is the first person that you should consult with regarding treatment alternatives for Ms. McKenzie?

_____

5. (6 points)
Who is the second person that you should consult with regarding treatment alternatives for Ms. McKenzie?

_____

6. (8 points)
When speaking with Ms. McKenzie, what information should you be most ready to provide? (choose top 3)
___ a. The least restrictive, least invasive, or most palatable treatment available to her.
___ b. The dosage of the treatment
___ c. What the treatment process is.
___ d. Who will manage the treatment.
___ e. When the treatment will begin.
___ f. When relief of symptoms can be expected to occur.
___ g. The side effects of the proposed treatment
___ h. The expected duration of the treatment.
___ i. The expected effect of the treatment.
___ j. How long will the treatment last without recurrence of symptoms.

Please print your name at the top of each page _____

7. (4 points)
When weighing the alternatives for treatment of Ms. McKenzie, whose opinion should you give the most weight?

_____

8. (4 points)
Are any of the treatment alternatives for Ms. McKenzie so extreme, controversial or invasive that they may require consultation with or permission of the court?
___ Yes
___ No

9. (4 points)
If required to provide justification for your choice of treatment, what are the most important issues that you should touch upon? (choose two)
___ a. This choice was Ms. McKenzie's preference.
___ b. This choice was the least invasive and least restrictive to the ward.
___ c. This choice would represent the provision of most remediation of symptoms with the least side effects.
___ d. This choice represented the most physical, social, ethical or religiously palatable choice for the ward.

Continue on the next page with Scenario Two

Please print your name at the top of each page _____

Scenario Two

Jack Hudson was involved in an automobile accident 15 years ago at age 38. Mr. Hudson has not awakened from the closed head trauma injuries that he sustained in the accident. Mr. Hudson has lived in a specialized long term care facility since that time. Although he is not on a respirator, his life is maintained by artificial hydration and nutrition. Eleven years ago his wife, Tracy divorced him and took their two children, Emily age eight and Christian aged five, to live in another state. She remarried three years later.

Mr. Hudson had an independent third party as his guardian until three weeks ago. At that time the independent third party guardian was asked to execute a Do Not Resuscitate Order and a Palliative Care Only order on Mr. Hudson's behalf. The independent third party guardian asked the court to remove her as guardian because she is "just too soft hearted" to "let Jack Hudson Die". The court has appointed you as the successor guardian.

10. (2 points)
Will you be using substitute judgment when you make medical decisions for Mr. Hudson if the family or documents are accessed to provide a frame of reference?
___Yes
___No

11. (6 points)
What main resources or documents will you review to determine the medical course of action? (choose 3 most important)
___ a. Outdated patient advocate forms
___ b. Living Will
___ c. Mr. Hudson's religious canons
___ d. Diaries
___ e. Journals
___ f. Family

12. (6 points)
In your search for information, which people should you consult first? (choose up to 3 of the primary sources)
___a. Parents
___b. Ex-wife
___c. Siblings
___d. Spiritual advisor prior to the accident
___e. Current spiritual advisor
___f. Physician
___g. Nurses
___h. Caregivers

Please print your name at the top of each page _____

13. (2 points)
Is there any value to consultation with Mr. Hudson's children/offspring?

___yes
___no

Scenario Three

Sarah Albright has been your ward for three years. Initially, Mrs. Albright came to you because her infarction dementia had caused her to be delusional and unable to retain information for a long enough period of time to make an informed consent, manage her income and assets, provide for her own safety, etc. Mrs. Albright also came to you with a diagnosis of hypertension, artheriosclerptic heart disease, and chronic obstructive pulmonary disease. Mrs. Albright was very ambulatory, social, and conscious of her forgetfulness. As guardian you placed Mrs. Albright into an assisted living environment. Mrs. Albright's improved nutrition, regular medical attention, compliance to her medication regimen, and daily contact with her peers has improved her mental status. Mrs. Albright is now able to retain information that is important to her. However, she continues to experience serious sundown symptoms.

Recently, Mrs. Albright's mammogram revealed a small mass in her left breast. Needle biopsy revealed that tumor is malignant and this type of cancer is very aggressive.

14. (4 points)
What standard of judgment will you be using in determining an appropriate medical course of action for Mrs. Albright?

_____

15. (6 points)
What documents will you seek to identify to assist you in making a medical decision in Mrs. Albright's behalf? Check all that apply.
___ a. Mrs. Albright's medical records
___ b. Mrs. Albright's Living Will
___ c. Advanced Directives signed by Mrs. Albright prior to her dementia
___ d. Living trust documents
___ e. Family medical histories
___ f. Literature regarding this form of cancer

Please print your name at the top of each page _____

16. (6 points)
What pieces of information would be most important to gather for comparison with Mrs. Albright's known wishes?
___ a. Treatments that were available when she made her wishes known originally.
___ b. Comparison of the older treatments with newer treatments and procedures.
___ c. Mrs. Albright's current attitude or perception of the disease
___ d. The importance of Mrs. Albright's physical appearance to her sense of identity
___ e. Mrs. Albright's plans and desires for the continuation of or the development of an intimate relationship with another person.
___ f. Side effects of treatments
___ g. Debility caused by the treatment.
___ h. Mrs. Albright's ability to tolerate the side effects and or debilitation that are caused by the treatment.
___ i. What will happen if no treatment is selected.
___ j. Mrs. Albright's ability to cooperate with the treatment to completion of the treatment plan.
___k. Treatment that will ameliorate symptoms of pain either due to the disease process or side effects, and debilitatio

17. (6 points)
What information would be MOST important to gather before you consult with Mrs. Albright regarding her medical condition? (choose three)
___a. The least restrictive/least invasive treatment that is available to Mrs. Albright.
___b. All the stages of the proposed treatment
___c. Rehabilitation needs
___d. Side effects of treatment
___e. Prosthetics or plastic surgery available that can disguise any disfigurement
___f. Where the initial treatment will take place
___g. How long Mrs. Albright will have to be away from home
___h. Who will care for her after the initial treatment

18. (4 points)
What social factors that should be taken into consideration before a final decision can be made? (check all that apply)
___a. Mrs. Albright's current marital status
___b. The ability of her partner to support her and accept the treatment decision.
___c. The effect of the treatment on Mrs. Albright's self-image
___d. Religious or faith-based restrictions or practices that affect the treatment being contemplated

Please print your name at the top of each page _____

19. (2 points)
Is Mrs. Albright's emotional investment in her physical appearance a factor in the decision making process?
___Yes
___ Not really

20. (2 points)
Who will make the final decision regarding Mrs. Albright's treatment?
___a. The physician
___b. Mrs. Albright
___c. The family
___d. The guardian

21. (2 points)
Whose opinion will be given the most weight during the decision-making process?
_____

Continue with questions on the next page

Please print your name at the top of each page: _____

Training Evaluation

1. I am more acquainted with the necessary steps in making a health care decision for my wards.
    a. Strongly agree.
    b. Agree.
    c. Neutral.
    d. Strongly disagree.

2. I better understand the concepts of substituted judgment and best interests.
    a. Strongly agree.
    b. Agree.
    c. Neutral.
    d. Strongly disagree.

3. I have a general understanding of the importance of using a protocol for making health care decisions.
    a. Strongly agree.
    b. Agree.
    c. Neutral.
    d. Strongly disagree.

4. I can better apply this protocol while making decisions for my wards.
    a. Strongly agree.
    b. Agree.
    c. Neutral.
    d. Strongly disagree.

5. The article was well-written, terms defined, and easy to understand.
    a. Strongly agree.
    b. Agree.
    c. Neutral.
    d. Strongly disagree.

6. I recommend another course on _____.

7. I serve as guardian in the state of _____.

8. I have been receiving appointments as a guardian for ____ years.