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**A BLUEPRINT FOR DISCUSSING
THE HEALTH CARE PROXY**

2004

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Dear Health Care Professional:

As you know, advance care planning provides individuals with the opportunity to discuss and plan for the types of health care decisions that may be made if they become seriously ill and need someone else to speak for them. The importance of providing individuals with information about end-of-life decision-making tools has been well documented.

Often, older persons and their families lack a clear understanding about the health care proxy directive. The health care professional is generally the primary source of information about this document. In order to provide the health care professional with suggestions about how to effectively address this topic, the Ravazzin Center on Aging has developed this guide. It is based on a protocol shown to be effective in increasing clients' comfort with and positive attitudes toward end-of-life discussions.

This booklet can be viewed as a "blueprint" for discussions about the health care proxy. Each person can modify his/her conversations with clients based on the individual situation. We hope that this booklet will help guide you when discussing this important issue, and we hope you will use your expertise to integrate this information into your discussion of advance care planning.

In the following pages, material in **bold** print provides general instructions to workers. Material in *italics* suggests a possible way to discuss the topic.

We hope you find these materials useful in conveying this important information to your clients.

Irene Gutheil
Director, Ravazzin Center

Janna Heyman
Senior Research Associate

Please make sure the client has the health care proxy form prior to these discussions. At the beginning of your visit, you could take the opportunity to explain to your clients that as part of your visit you would like to discuss the health care proxy with them. Below is an example of a way to initiate this discussion.

Example of a question to ask: *Have you thought about the possibility that there may come a time when you will be unable to help make decisions about your health care?*

If “Yes,” go to 1.

If “No,” go to 3.

1 *Have you talked with anyone about this?*

If “Yes,” go to 2.

If “No,” go to 3.

2 *With whom? What was that like for you?*

3 *Have you heard the terms health care proxy and living will?*

If “Yes,” go to 4.

If “No,” go to 5 on the next page.

4 *In your own words, what is your understanding of what it (they) is (are)?*

Now is an opportunity for you to provide a complete definition and to correct any misconceptions. [These documents are often not fully understood and may be confusing.]

Advance directive is the general term that refers to: 1) a living will and 2) a health care proxy. These documents give instructions about the medical care you would want in case you are unable to speak for yourself due to serious illness or incapacity.

A living will lets you put in writing your wishes about the medical treatment you want at the end of your life if you are unable to communicate these wishes yourself. This document is to guide your loved ones and doctors in deciding how aggressively to use medical treatment at end of life.

A health care proxy is a document that allows you to appoint someone you trust to make decisions about your medical care if you cannot do so yourself. The person you appoint is authorized to deal with all medical situations when you cannot speak for yourself, not only end-of-life decisions. In the event you become permanently or temporarily incapacitated - - after an accident, for example - - as well as if you become irreversibly ill, this person can speak for you. This person is called your health care agent.

Go to 6 on the next page.

5 Explain the two documents and the differences between them.

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A living will lets you put in writing your wishes about the medical treatment you want at the end of your life if you are unable to communicate these wishes yourself. This document is to guide your loved ones and doctors in deciding how aggressively to use medical treatment at end of life.

A health care proxy is a document that allows you to appoint someone you trust to make decisions about your medical care if you cannot do so yourself. The person you appoint is authorized to deal with all medical situations when you cannot speak for yourself, not only end-of-life

decisions. In the event you become permanently or temporarily incapacitated - - after an accident, for example - - as well as if you become irreversibly ill, this person can speak for you. This person is called your health care agent.

- 6 *There is another document you have probably heard about: The Do-Not-Resuscitate (DNR) Order. This is a written instruction from a doctor to health-care providers telling them not to perform cardiopulmonary resuscitation or related procedures on a patient. It is different from a health care proxy or living will because it is written and signed by the doctor. You are the only one who can sign your health care proxy or living will.*

Health care proxies are for everyone, not just someone who is older or who is sick. I myself have a health care proxy.

Today, we are going to focus on the health care proxy, because this is the directive that New York State recognizes.

Do you have a health care proxy?

If “Yes,” go to 11 on page 6.

If “No,” go to 7.

- 7 **Take this opportunity to find out why s/he does not have one.**
- **If the individual says there is no one to name as an agent, go to 9 on the next page.**
 - **If the individual is not sure about naming an agent, has doubts about the document or another reason other than no one to name, go to 8 on the next page.**

- 8 *Perhaps our talking about it will help you decide if this is something that would be helpful to you in the future. Let me tell you a little about the role of the person you would name.*

The role of the Health Care Agent is to:

- *Make medical decisions if you lose capacity to make them on your own (The health care agent is consulted when doctor determines you are unable to make medical choices independently.)*
- *Speak for you only if you are unable to speak for yourself. For example, if you are temporarily incapacitated after an accident or you are unable to speak because you are in a coma*
- *Have legal authority regarding medical decisions*
- *Know about your wishes regarding types of treatment you wish to receive or not receive*

Perhaps we could talk about the kinds of things you would look for in someone who you would trust to speak for you

What are some of the difficulties in choosing someone (e.g., choosing a family member; concerns about burden placed on a child; concerns or discomfort about discussing end-of-life wishes)?

Do you feel there is someone who could serve as your health care agent?

If there is someone, go to 12 on page 6.

If there may be someone to name, continue with 9.

If there is absolutely no one, go to 10 on the next page.

- 9 **If the individual says there may be no one to name as an agent:** *Let me tell you a little about the role of the health care agent so you can be sure there is no one you could name.*

The role of the Health Care Agent is to:

- *Make medical decisions if you lose capacity to make them on your own (The health care agent is consulted when doctor determines you are unable to make medical choices independently.)*
- *Speak for you only if you are unable to speak for yourself. For example, if you are temporarily incapacitated after an accident or you are unable to speak because you are in a coma*
- *Have legal authority regarding medical decisions*
- *Know about your wishes regarding types of treatment you wish to receive or not receive*

This will help insure that your wishes will be followed. You will have the peace of mind that comes with knowing your wishes will be respected even if you are unable to speak for yourself.

Perhaps we could talk about the kinds of things you would look for in someone who you would trust to speak for you.

Do you still feel there is no one you would want to name as an agent?

If there is someone who could serve as an agent, go to 12 on the next page.

10 **If there is absolutely no one in their life who could serve as an agent:**

Perhaps having a living will is more important for you than a health care proxy. A living will lets you put in writing your wishes about the medical treatment you want at the end of your life if you are unable to communicate these wishes yourself. This document is to guide doctors in deciding how aggressively to use medical treatment at end of life. The living will does not carry the same legal weight in New York that the health care proxy does but it may be useful to provide guidance to your health care providers.

The other material for this information session relates to the health care proxy, which is not applicable to your situation. Do you have any other questions about the living will before we end our discussion? You may want to discuss this further with your doctor.

Please thank the client and end the information session.

11 *Would you like to talk a little about your health care agent?*

Who is the person you named as your health care agent?

What is his/her relationship to you?

What do you think she/he would do if you were unable to express your medical decisions?

You should then add to this to provide complete definition(s) or correct any misconceptions.

The role of the Health Care Agent is to:

- *Make medical decisions if you lose capacity to make them on your own (The health care agent is consulted when doctor determines you are unable to make medical choices independently.)*
- *Speak for you only if you are unable to speak for yourself. For example, if you are temporarily incapacitated after an accident or you are unable to speak because you are in a coma*
- *Have legal authority regarding medical decisions*
- *Know about your wishes regarding types of treatment you wish to receive or not receive*

Continue with 12 below.

12 **You can then ask each individual if he/she feels comfortable talking about this topic.**

How comfortable is it/was it/would it be for you to name someone to make medical decisions for you?

What makes it comfortable/uncomfortable for you?

Any fears in doing so? If so, why?

Are you thinking about why you should plan now?

If you want the designated agent to make decisions for you if you are unable to speak for yourself, you need to discuss your wishes now so he/she will know what you want.

This will help insure that your wishes will be followed. You will have the peace of mind that comes with knowing your wishes will be respected even if you are unable to speak for yourself.

The person you choose to speak for you will have a frame of reference or guide to help him/her. This may eliminate his/her stress and guilt.

You should ask the following questions only if the individual has a family. If the person has no family, go to 13.

Who are the decision makers in your family?

Is one of them the main decision maker?

How comfortable do you feel talking with her/him about your wishes related to future medical care?

Have you discussed with her/him about what your specific wishes are?

13 *Let's review the kind of decisions agents can and cannot make:*

The health care agent has the legal right to make decisions if you are unable to speak for yourself regarding:

- 1) health care decisions for you if you cannot speak for yourself*
- 2) artificial nutrition – if your wishes are known*
- 3) artificial hydration – (intravenous fluids) – if your wishes are known*
- 4) stopping life sustaining treatment (e.g., renal dialysis, ventilator)*

The health care agent does not have the legal right to make decisions regarding:

- 1) voting for you in an election*
- 2) making financial decisions*
- 3) making decisions for you if you still have the capacity to communicate*

Let's review some key discussion points on medical, legal, and values issues:

- ▲ Medical issues including the kinds of decisions individuals may be called upon to make
 - withholding or withdrawing treatments, including Do-Not-Resuscitate, tube feeding, hydration, ventilator (breathing machine), surgery
 - Timing – why it is important to discuss early on in the process; not waiting until there is a crisis and people are too upset to talk or are unable to state their wishes
 - Dealing with doctors and nurses – health care agents may need to ask for information about effects of treatment. They may have to advocate to make sure your wishes are followed.

- ▲ Legal-type issues
 - Naming someone
 - Substitute person to serve as a back-up
 - Do not need a lawyer to complete the form
 - Need two witnesses to sign health care proxy
 - Do not need to notarize the form
 - Does not deal with financial issues
 - Cannot make nutrition, hydration decisions if your wishes about these are not known
 - Who should receive a completed copy
 - Can cancel health care proxy form or change designated health care agent

- ▲ Personal Values
 - *One way to help you think about what you would want or not want to have done if you were seriously ill or dying is to think about what you value most in life.*
 - *What do you value most in life? What makes your life worth living?*

If the individual needs help getting started, you could mention some of the things people often say:

- *Connections with others*
- *Ability to communicate with others*
- *Ability to express my wishes*
- *Ability to make decisions*

*In thinking about these things you value most, under what circumstances would life be unbearable without them? For example, if there came a time when you could not _____ (**complete phrase based on what s/he says is unbearable**), and the ability to do this would probably not come back, would you say that was a time when you would not want medical treatment that would extend your life?*

How important is it to you to have your wishes carried out? Talking with loved ones about what you value most in life can help them make decisions for you if that should become necessary.

It is important to acknowledge the difficulties most people have in talking about end-of-life decisions.

Question to ask to continue the dialogue:

Why is it difficult to discuss end-of-life with your loved ones?

Here are some examples of concerns people may have:

- *People are afraid to discuss death. At times they'll believe that talking about death will bring bad luck or they're afraid that it will bring death closer.*
- *People may not want to talk about sad things with their loved ones.*

Here are some suggestions on how to begin the conversation.

- *Don't wait for the perfect moment; there never is a perfect moment*

- *It is OK not to have the perfect lead-in sentence*
- *Decide when and where you want to have the conversation*
- *Decide whether you want to speak with one individual or the whole family.*
- *Sometimes it is helpful to start by discussing someone else's situation*
(e.g., Do you remember what happened to?)

We've talked about a lot of things today. Do you have any questions about any of the things we've talked about?

(Answer questions)

I hope our discussion has helped you better understand the process of selecting someone to make your medical decisions in the future if you lose the capacity to do it yourself. You may want to discuss this further with your family or doctor.

NOTES

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