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Anemia

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Advance care planning

Specify your wishes now

By Thaddeus Mason Pope, JD, PhD

What will happen if you experience a serious illness that prevents you from making your own health care decisions? How will you ensure that you receive the kind of care you want? Will your family know enough about your values to feel comfortable making medical decisions on your behalf? To adequately address these questions, every adult Minnesotan should do advance care planning (ACP).

Advance care planning is important

At some point, serious illness will probably prevent you from being able to make or communicate your own health care decisions. You will lose decision making "capacity," the ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. You will be unable to direct your medical care. Unless you plan for this, you will likely be treated in ways and in settings that you do not want.

Fortunately, you can take steps, now, to make your "voice" heard later. Advance care planning (ACP) is the process of discussing and documenting your end-of-life wishes. Because ACP allows you to specify in advance how you want to be treated, it helps assure that you receive medical care aligned with your values and preferences. The goal is to ensure both that you get the care you want and that you avoid the care you do not want.

ACP is a multistep process. First, have multiple conversations with your family, friends, and clinicians to explore and consider your health care values and goals. For example, if you were dying, how important would it be to avoid pain and suffering, even if it means that you might not live as long? How important is it to be alert, even if it means that you might be in pain? Would you rather be more conscious and have some pain? Or would you rather have less pain and be groggier?

Once you have identified your values and goals, you need to communicate them. There are three main objectives: 1) choose your health care agent, 2) document your preferences and values, and 3) translate your preferences and values into medical orders.

Choose your own health care agent. When you are unable to make your own medical decisions, you will want to select someone whom you trust to make those decisions on your behalf. If you do not make a selection, one will be made for you. But that is a risky approach. The person whom someone else (like a probate court judge) selects may be unaware or unwilling to follow your wishes. Choose your own health care agent.

In Minnesota the main written legal instrument for identifying a substitute decision maker is the "health care directive." This is a

simple form that includes a health care power of attorney by which you can formally appoint your "health care agent." You should probably also designate one or more alternate back-up agents, in case your first named agent is not reasonably available to serve.

By appointing an agent, you are not surrendering any control. Your agents will not have authority to make health care decisions for you, unless you lack decision-making capacity. If you can decide and speak for yourself, clinicians will look to you, not to your agents. Furthermore, even when they have authority, your agents must make health care decisions for you based both on any instructions that you provide in your health care directive and on any wishes you made known to the agent. Finally, note that health care directives cover only health care decisions. They have no effect over financial affairs that are unrelated to your health care.

Every adult Minnesotan should have an advance health care directive.

Document your preferences and values. In the same health care directive through which you appoint your health care agent, you can also include health care "instructions." This part of the directive used to be known as a "living will." These instructions are written statements of your values, preferences, or guidelines regarding health care. Typically, these specify what medical treatment you do or do not want under certain stated medical circumstances.

For example, would you want to be maintained on a mechanical ventilator (breathing machine), if you were permanently unconscious? Would you want medicine to treat pneumonia, if you had the incurable brain illness known as Alzheimer's and were unable to recognize your family or carry on a conversation? The better forms and worksheets go beyond a narrow focus on specific interventions and also help you more broadly define the things that make your life worth living.

While most health care directive instructions are about medical treatment, you can also include two other types of instructions. First, you can clarify your intentions regarding anatomical gifts. Do you want to donate any parts of your body, including organs, tissues, and eyes when you die? Second, you can clarify your intentions regarding funeral practices. What do you want to happen with your body (burial, cremation)?

Translate your preferences and values into medical orders. Every adult Minnesotan should have an advance health care directive. But some Minnesotans should not stop there. In addition, those who are already seriously ill or frail with a life-limiting or terminal illness should also have Provider Orders for Life-Sustaining Treatment (POLST). POLST is designed to document wishes only in the final stages of life. So, it is appropriate only when death within the next year would not be unexpected.

POLST has several advantages. First, while there are dozens of advance directive forms, there is a single standardized Minnesota POLST. It is only one double-sided page, usually on bright pink paper. This uniformity and simplicity makes the form easy to find and easy to follow. Second, POLST follows the person in any care setting (hospital, nursing home, residence). Third, unlike an advance health care directive, POLST is intended to apply immediately, not only upon the satisfaction of certain specified conditions.

Readers may recall the August 2015 case in which Maplewood paramedics stopped resuscitation efforts on a 71-year-old nursing home resident at her husband's request. Those paramedics were later placed on administrative leave. Emergency workers like EMTs and paramedics are legally required to prolong the lives of dying patients unless they have a specific order from a physician. A POLST is such an order. An advance health care directive is not.

Periodically update your planning documents

ACP is not a one-time event but an ongoing process. As your life circumstances change, so may your health care preferences. Experts recommend that you revisit your ACP documents at any of the five D's: every decade, at the death of a loved one, divorce, new diagnosis, or significant decline in condition. You can always change your

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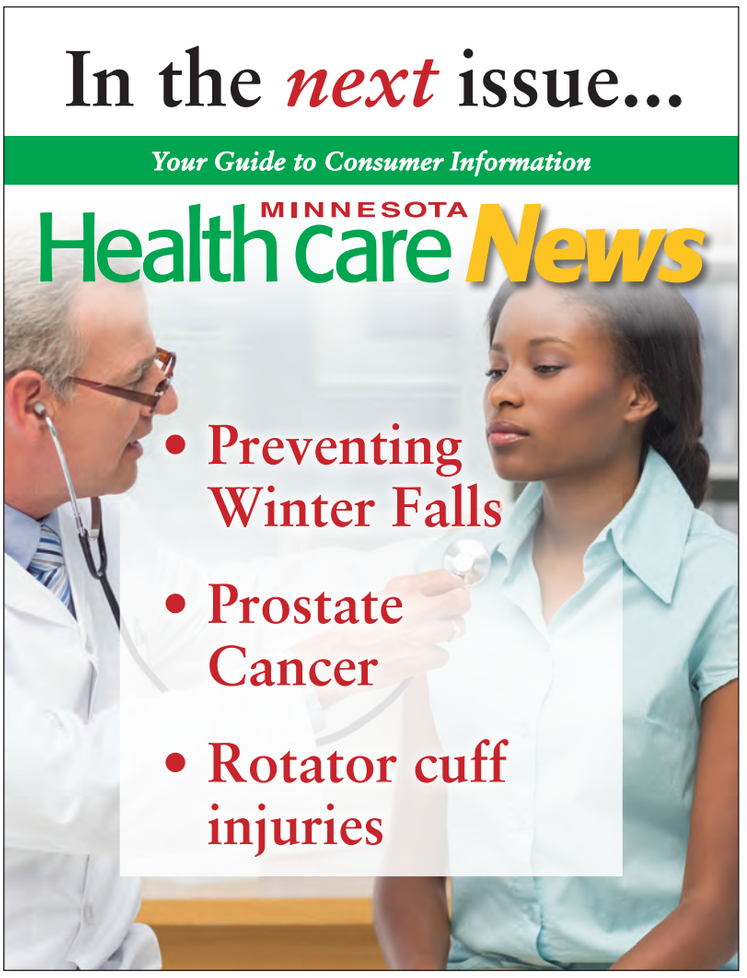

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mind about the care you want by revoking or updating your health care directive or POLST.

Local ACP resources

While completing a health care directive is a standard part of any estate planning discussion, you do not need a lawyer. Numerous ready-to-use resources are available to guide and record your advance care planning. First, several Minnesota state government agencies (like the Department of Health and the Attorney General's Office) provide ACP materials. Second, most area hospitals and health insurance companies share ACP tools and forms both with their patients and on their websites. Third, many religious organizations distribute their own ACP materials. Fourth, dozens of expert nonprofit organizations offer their ACP resources for free. Some of the most effective and respected are listed in the sidebar.

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Medicare coverage is coming

For decades, physicians and other clinicians have been reluctant to take the necessary time to carefully address patients' wishes, goals, and fears regarding their end-of-life care. After all, they are paid more for doing, than for just talking. While some private insurers already pay for ACP consultations, this year, Medicare announced plans to pay physicians to counsel patients about end-of-life options beginning on Jan. 1, 2016. Since most private insurers follow Medicare's lead, ACP should soon be far more available.

Summary

Plan your future medical care. Discuss your end-of-life wishes and put them in writing. These are not easy issues to talk about. But they are some of the most important discussions that you will ever have. Your wishes cannot be followed, if no one knows what they are.

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Advance Care Planning Resources

ABA Consumer's Toolkit: www.americanbar.org/groups/law_aging/resources.html
Conversation Project: theconversationproject.org
Five Wishes: www.agingwithdignity.org/five-wishes.php
Honoring Choices Minnesota: www.honoringchoices.org
National Health Care Decisions Day: www.nhdd.org
POLST Minnesota: www.polstmn.org