A Guide for Surrogate Decision-Makers

When a person becomes unable to make decisions about their medical care because of an accident or serious illness, someone else must make decisions about that person's care for them. We call this a "surrogate decision-maker". The surrogate decision-maker may be:

- A **Health Care Agent** appointed in an advance directive, or
- A patient's **Legal Next of Kin** identified under the Virginia Health Care Decisions Act

Regardless of how you come into the role of surrogate decision-maker, your responsibility is to **do your best to make the same decisions that the patient would make if they could.**

As a surrogate decision-maker, you may be asked to:

- Accept, decline, or stop treatments (including life-prolonging interventions)
- Make decisions about having the patient admitted to or discharged from a hospital, nursing home, or other facility

This Guide is meant to help the surrogate decision-maker make informed, ethical medical decisions for another person.

Step 1: When possible, be prepared

Having to make healthcare decisions for someone else can happen suddenly. Making those healthcare decisions before you've had a conversation with that person about their goals, values, and care preferences can be very difficult.

Don't wait until a health crisis has already happened. Whenever possible, have conversations with the person for whom you may be a surrogate decision-maker when there is time for thoughtful reflection and clarification.

Questions to explore with the patient: We may not always be able to predict what medical situations lie ahead, but we can discuss "quality of life." Consider asking the patient these questions:

- What experiences have you had with people who are seriously ill, and what did you learn from those experiences?
- What brings your life meaning?
- What are you willing – or not willing – to go through to live longer?
- What level of physical loss of function would you be willing to live with in exchange for more time?
- What level of mental loss of function would you be willing to live with in exchange for more time?

- What abilities are so important to you that you can't imagine living without them?
- What are your biggest fears or worries when it comes to your health?
- What matters most if you only have weeks to months to live?
- Under what circumstances might you choose to have your care focus on comfort rather than on living longer?

Important:

- Statements like "do everything," "keep me comfortable," or "don't leave me hooked up to machines" are vague — **ask for clarification** and examples.
- **Revisit these conversations over time.** Preferences often change depending on someone's health status.
- Consider suggesting that the individual complete an advance directive. An advance directive is a legal document that informs healthcare providers about the patient's healthcare choices.

For guidance on completing an advance directive and links to advance directive forms, visit the UVA Advance Care Planning webpage at https://www.uvahealth.com/patients-and-visitors/advance-directive.

Step 2: Gather the medical facts

Good decisions require a clear understanding of the medical situation. Because many medical teams may be involved, it can help to ask that one clinician provide regular updates about the patient's condition.

Questions for the care team:

- How has their medical condition changed?
- What are the expected benefits, risks, and side effects of this treatment?
- How will this treatment help the patient get better?
- What does "get better" look like, and about how long will it take?
- How will this affect their quality of life?
- Is this consistent with the patient's values, goals, and preferences?
- If we try this treatment, can it be stopped later on?
- If we don't try this treatment, what will happen?
- What information do you need in order to make a recommendation?
- What do you recommend and why?

Practical guidance:

- Keep asking for clarification until you understand.
- If you need time to think about what you've been told or to discuss with others, ask if that's possible.
- Consider a **time-limited trial** to see if a treatment leads to improvement or if the patient's condition doesn't improve or gets worse despite the treatment.

Step 3: Focus on values and preferences

Your primary duty is to reflect what the patient would want.

Sources of guidance:

First, look to Advance Care Planning, "ACP", documents such as advance directives, living wills, healthcare powers of attorney, Durable Do Not Resuscitate (DDNR) order, or POLST orders (doctor's orders about CPR and other treatments for use in the out-of-hospital setting).

If the patient has not left specific documents that could guide your decision-making, use your knowledge of the person to help guide your decisions, considering:

- Past conversations about health, illness, or end-of-life care
- Statements made about others' medical situations
- Past decisions they made for themselves or others
- Values, beliefs, and priorities
- Cultural or religious perspectives
- Tolerance for disability, discomfort, and/or dependence
- What makes life meaningful to them

Ask yourself: What would this person say about this situation? You're always welcome to talk with others who know the patient well to help you understand what the patient would likely want.

Step 4: Make the decision

After gathering medical information and reflecting on the patient's values, in order to make decisions you should:

- Combine the **clinical facts about their condition with the patient's preferences**
- Weigh benefits vs. burdens from the patient's perspective
- Choose the option that best lines up with who the person is

Your task is not to be certain; it is to be faithful to the person you represent.

- Clinicians provide medical expertise
- **You provide knowledge of the person**

Together, these form the basis of good decision-making.

Step 5: Use available support

This role of surrogate decision-maker often arises during times of crisis, uncertainty, or strong emotion. It can be difficult, and you aren't expected to do this alone.

Helpful resources:

- Request a **family meeting** with the care team
- Ask for a **palliative care** consultation for symptom management and goal alignment (see our palliative care webpage at https://www.uvahealth.com/specialties/palliative-care)
- Seek a **second medical opinion**
- Consult with **chaplaincy or spiritual care**
- Request an **ethics consultation** (a service that helps patients, families, and medical staff resolve conflicts or uncertainties).If there is any uncertainty or if there is conflict, you can ask a member of the healthcare team to ask for an ethics consultation for you, or you can call the hospital operator and ask for an ethics consult directly.