

ALLINA HEALTH

Discussion guide

Advance care planning



Allina Health 

Advance care planning

Any of us could think of a time when we might be too sick to communicate our wishes. For example, after a car accident or heart attack we might need to depend on others to make important decisions about our care. How can we guide our loved ones so they feel confident making decisions?

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Advance care planning helps your loved ones gain a better sense of your values, preferences and wishes related to health care. It provides information to others about your health care wishes in case illness or injury prevents you from telling them yourself.

Advance care planning is a process to

UNDERSTAND: Learn about health care treatment options and discuss these with your family and close friends.

CLARIFY: Talk through your health care goals with your family and close friends so they understand your wishes.

WEIGH YOUR OPTIONS: Think about what kind of care and treatment you would want, who you would want to care for you and where you would want to receive care.

MAKE DECISIONS: Decide if you want to appoint a health care agent. Decide if you want to put your wishes in writing in a health care directive.

COMMUNICATE: Share your wishes and any documents with your family and close friends, your health care agent and your health care provider.



Allina Health is committed to you

Advance care planning is one way we support you as your partner in health care. At Allina Health, we commit to being your partner in health care throughout your life. We will:

- Encourage you to have an advance care planning discussion with your family and close friends.
- Make sure your advance care plan is completed the way you want. You may choose to have an advance care planning discussion, you can assign a health care agent, and/or you can complete a health care directive form (living will).
- Make sure your health care wishes will be available wherever you receive care at Allina Health. This is done through the electronic health record. In addition, we recommend you share copies of your plan with family, close friends and your health care agent.

When you have a health care directive, we will do our best to honor your wishes and choices for medical care and treatment every step of the way.

How to begin

- Use this guide and any other resources you may find.
- Choose your health care agent(s).
- Prepare for a discussion with your health care agent(s), family members and close friends using the following discussion.
- Attend one of our free advance care planning classes.

THINGS TO THINK ABOUT

Have you chosen the right person to be your health care agent?

You can choose someone, called a health care agent, to make health care decisions for you if you can't communicate them on your own. When deciding on a health care agent, choose someone who is at least 18 years old and someone whom:

- you trust
- has similar beliefs and values about medical care and death or dying or is willing to carry out your wishes even if they are different than his or her own
- is not easily intimidated by family, close friends or health care providers
- will be an advocate for you
- can make decisions under stress
- can cope with making difficult life and death decisions, including making decisions that would allow you to die.

Allina Health offers free classes to assist you in having advance care planning discussions and write a health care directive. Call 612-262-2224 or 1-855-839-0005 to register for a class.

Your health care agent will represent your wishes and make your health care decisions **ONLY** if you are unable to do so due to illness or injury. Your health care agent will:

- Make choices for you about your medical care. This includes starting or refusing tests, medicine and surgery. If treatment has already started, your health care agent can continue it or stop it based on your instructions.
- Interpret any instructions you have made based on his or her understanding of your wishes, values and beliefs.
- Review and release your medical records as needed for your medical care.
- Arrange for your medical care and treatment in any location he or she thinks is right, such as a nursing home or residential facility for long term care.
- Decide which health care providers and organizations provide your medical treatment, including care and treatment for mental health conditions.
- Make medical decisions if you are pregnant.

Portions of the health care agent information were developed by a group of professionals with expertise in law, health care, life and death health care decision making, and plain language materials development with the leadership of Marlene S. Stum, PhD, University of Minnesota Extension (updated 2006).



Once you have chosen your health care agent and reviewed his or her roles and responsibilities, talk to your agent about advance care planning using the following discussion questions.

What do you hope to achieve in going through the advance care planning process?

Think about what you want to talk about with your loved ones about your health care wishes. For you, what makes life worth living or when would life not be worth living? Plan to have this discussion when you are feeling well, before a crisis or emergency.

Have you had past experiences with a family member or friend, or heard of another situation where a decision had to be made about a health care choice?

Think about the health care decisions that had to be made during these difficult times. What would you want your loved ones to do on your behalf if you were in a similar situation? Talking about this can help your loved ones make health care decisions for you at an emotionally difficult time.

What fears or worries do you have about possible future medical care?

Some people worry about being a physical or financial burden to their loved ones. Others have fear about pain and prolonged suffering. What fears or worries do you have?

For discussion

You have suffered a head injury in an automobile accident that left you in a permanent vegetative state. You would not be able to communicate your wishes to your family. What would you decide about health care for yourself in this situation?

What would you want for yourself if you were injured or suddenly became ill and were unable to speak for yourself?

For example, if you were in a serious car accident:

- Would you want life support treatment?
- Would you want medical treatments such as a ventilator/respirator, feeding tube or cardiopulmonary resuscitation (CPR)?
- How long would you want to receive these treatments?
- What outcome would you hope for by having these treatments?

For discussion

You have had a stroke and cannot communicate with your family about the kind of medical care you want. Your heart and other vital organs can continue to function with medical care for years, even decades. What type of treatment would you want?

For people with an illness: You will face making choices about your medical care long before you are at the end of life. If you became so sick from an illness that you might die at some point in the future, what kind of care would you want?

Think about:

- your wishes for the quality and length of your life
- your wishes for medical treatment, including pain control
- how successful the treatment might be and how easy or hard the treatment may be for you.

What kind of side effects will you have with the treatments? How long will you live with or without the treatment (such as antibiotics and other medicines, blood transfusion, temporary or permanent tube feeding/artificial fluids, temporary or permanent respirator, surgery, radiation, amputation, dialysis, chemotherapy, cardiopulmonary resuscitation – CPR)? Do you need more information about these treatments before making a decision?

For discussion

Imagine in the future you are diagnosed with dementia. Would you want to continue your life by artificial means? If you cannot feed yourself, should a feeding tube be used?

Think about where and how you would want to spend your final days.

What would your choices be for location (home, hospital, nursing home) and type of care (hospice or palliative care), organ donations and funeral arrangements?

For discussion

You have terminal cancer and need to decide if your goal is to live your final days in comfort or to extend your life as long as possible. What type of care would you want to receive? Where would you want to spend your final days – at home, in a nursing home or at a hospice residence?

What personal and religious/spiritual beliefs and values shape how you make choices about health care?



HEALTH CARE DIRECTIVES

Putting your wishes in writing is the best way to help make sure those wishes are followed if you can't communicate because of illness or injury. If you choose not to put your wishes in writing, your health care agent and health care provider will make decisions based on your spoken directions or what he or she considers to be in your best interests.

FREQUENTLY ASKED QUESTIONS ABOUT HEALTH CARE DIRECTIVES

How do I create a health care directive?

There are forms for health care directives. You don't have to use a form, but your health care directive must meet the following requirements to be legal:

- be in writing and dated
- state your name
- be signed by you or someone you authorize to sign for you, when you can understand and communicate your health care wishes
- have your signature verified by a notary public or two witnesses
- include a health care agent to make health care decisions for you and/or instructions about your health care choices
- before you prepare or revise your directive, talk about your health care wishes with your doctor, health care agent, family and close friends.

What can I put in my health care directive?

You have many choices about what to put in your health care directive. For example, you may include:

- the person you choose as your primary agent to make health care decisions for you (it is recommended you name an alternate agent in case the first agent is unavailable)
- how you want your agent or agents to make decisions
- your goals, values and preferences about health care

- the types of medical treatment you would want (or not want)
- where you want to receive care
- instructions about artificial nutrition and hydration
- mental health treatments that use electroshock therapy or neuroleptic medicines
- instructions if you are pregnant
- donation of organs, tissues and eyes
- funeral arrangements
- who you would like as your guardian or conservator if there is a court action.

You may be as specific or as general as you wish. You can choose which issues or treatments to deal with in your health care directive.

What can't I put in my health care directive?

There are some limits about what you can put in your health care directive. For example:

- your agent must be at least 18 years old
- your agent cannot be your health care provider, unless the health care provider is a family member or you give reasons for the naming of that person as your agent
- you cannot request health care treatment that is outside of reasonable medical practice
- you cannot request assisted suicide.

How long does a health care directive last?

Your health care directive lasts until you change or cancel it. As long as the changes meet the requirements listed, you may cancel your directive by any of the following:

- provide a written statement saying you want to cancel it
- destroy it
- tell at least two other people you want to cancel it
- write a new health care directive.

How often should I review my health care directive?

You should review and update or complete a new health care directive form on a regular basis, at least every five years. We also recommend you review your health care directive:

- if there is a major family change, such as divorce or death
- if you develop a serious health condition
- if your health gets significantly worse, especially if you are unable to live on your own.

Who should get copies of my health care directive?

Make sure to give copies of your health care directive to your

HEALTH CARE PROVIDER: At Allina Health, this becomes part of your electronic health record and is accessible by Allina Health doctors and staff who are part of your care team.

HEALTH CARE AGENT(S): Help them understand their responsibilities and decision-making powers and your wishes.

FAMILY AND CLOSE FRIENDS: Tell them who you have named as your health care agent and any other information you are willing to share.

For information on state health care directives, contact your health care provider, your attorney or visit the following websites:

MINNESOTA: health.state.mn.us/divs/fpc/profinfo/advdir.htm

IOWA: uihealthcare.org/otherservices.aspx?id=16035

NORTH DAKOTA: nd.gov/dhs/info/pubs/docs/aging/aging-healthcare-directives-guide.pdf

SOUTH DAKOTA: finance.cch.com/tools/downloads/sdlivingwill.rtf

WISCONSIN: dhs.wisconsin.gov/forms/advdirectives/index.htm

US LIVING WILL REGISTRY: uslivingwillregistry.com/

Or call

OFFICE OF OMBUDSMAN FOR LONG TERM CARE

1-800-657-3591 or 651-431-2555

MINNESOTA BOARD ON AGING

1-800-882-6262 or 651-431-2600



GLOSSARY

ADVANCE CARE PLANNING: A process and discussion over time where individuals clarify their goals and values, understand health care choices and options of care and communicate future medical treatment preferences, including end-of-life care.

HEALTH CARE DIRECTIVE (ADVANCE DIRECTIVE/LIVING WILL): Legal forms you complete to describe choices for future health care if you become unable to make these decisions yourself.

ANTIBIOTICS: Medicines used to treat illnesses caused by infections and to relieve symptoms.

ARTIFICIAL NUTRITION AND HYDRATION: Liquid food and fluids given through a tube put in your vein or stomach when you can no longer eat or drink.

DECISION MAKING CAPACITY: The ability to take in information, understand its meaning and make an informed choice using the information.

CARDIOPULMONARY RESUSCITATION (CPR): A life-saving treatment used to attempt to restore heart rhythm and/or breathing when they have stopped. CPR uses rescue breathing (someone breathing into your mouth) and chest compressions (someone pressing on your chest) to try to revive you. In addition, you may need medicines and electrical shock to the heart delivered from a defibrillator machine).

COMFORT MEASURES/COMFORT CARE: Medical care provided with the primary goal of keeping a person comfortable rather than prolonging life. Comfort measures are used to relieve pain and other symptoms.

DIALYSIS: A treatment that removes waste from the body usually done by your own kidneys. Dialysis is needed when your own kidneys can no longer take care of your body's needs.

HEALTH CARE AGENT (PROXY): Your agent is a trusted individual chosen by you to make health care decisions on your behalf only if you are unable to make decisions yourself.

INTRAVENOUS (IV) FLUIDS: A fluid given through a small plastic tube (catheter) inserted directly into the vein.

INTUBATION/INTUBATE: Placing a tube down an individual's windpipe to assist in breathing. Intubation is needed for mechanical ventilation.

MECHANICAL VENTILATION: Mechanical ventilation is used to support or replace the function of the lungs. A ventilator (or respirator), is a machine attached to a tube inserted through the mouth and into the windpipe, forcing air into the lungs. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important for them. For the person dying however, mechanical ventilation often prolongs the dying process until some other part of the body fails. It may supply oxygen but it cannot improve the underlying condition.

POLST (PROVIDER ORDER FOR LIFE SUSTAINING TREATMENT):

A brightly colored provider order form used to write medical orders to honor life-sustaining treatment wishes for seriously ill patients.

TUBE-FEEDING (ENTERAL FEEDING): Delivery of fluids and/or nutrition by way of a tube placed into the stomach or intestines.

On a short-term basis, the tube (nasogastric, or NG-tube) is placed into the nose, down the throat and into the stomach. For long-term feeding needs, the tube is placed directly into the stomach (gastric tube, or G-tube).

Pocket card

PATIENT INFORMATION

Name

Address

Phone (home)

Phone (other)

I have a health care directive on file at:

CONTACTS

Doctor: Name, phone

Emergency contact: Name, phone

Health care agent: Name, phone, address

Health care agent (alternate 1): Name, phone

Trim at dotted line. Then fold in half and fold in half again.



Roles and responsibilities of a health care agent

Name of health care agent _____,

I have named you as my health care agent.

Thank you for agreeing to be my health care agent and taking on this very important responsibility for me. I have chosen you to be my health care agent because you are at least 18 years old and, someone whom:

- I trust
- has similar beliefs and values about medical care and death or dying or you are willing to carry out my wishes even if they are different than your own
- is not easily intimidated by family members, close friends or health care providers
- will be an advocate for my interests
- can make decisions under stress
- can cope with making difficult life and death decisions including making decisions that may allow me to die.

In addition, as my health care agent you may need to represent my wishes and make health care decisions on my behalf due to illness or injury. I am giving you permission to:

- Make choices for me about my medical care. This includes starting or refusing tests, medicine and surgery. If treatment has already begun, you may continue it or stop it based on the instructions I have discussed with you.
- Interpret any instructions based on your understanding of my wishes, values and beliefs.

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Roles and responsibilities of a health care agent (*continued*)

- Review and release my medical records and personal files as needed to help you in deciding care needs.
- Arrange for my medical care and treatment in any location you think is right, which may include the need to live in a nursing home or residential facility for long-term care.
- Decide which health care providers and organizations provide my medical treatment including care and treatments for a mental health condition.
- Make medical decisions for me and my unborn child, if I am pregnant.

In the future it will be important for us to have ongoing advance care planning discussions so I can be assured you are confident in your abilities to make decisions consistent with my wishes on my behalf.

Name

Date



Advance care planning checklist

- understand your health situation
- identify your health care agent(s)
- have advance care planning discussions with your health care agent
- attend a free advance care planning class for assistance with advance care planning discussion and/or help in completing a health care directive when needed
- complete the legal health care directive
- distribute copies of your health care directive to your family, health care provider, medical record, etc.
- review your health care directive on a regular basis at least every five years.

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allinahealth.org/acp