EDUCATION

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 is the process of giving information to others about your health care choices in case illness or injury prevents you from telling them yourself. Talk with members of your care circle (family, friends or others close to you) about your health care choices. This is a time for you to share what kind of care and treatment you do or do not want, and your wishes, goals and values and how they relate to your health care choices for the future.

Advance care planning is a process to:

UNDERSTAND: Learn about health care treatment options and talk about these with your health care provider and care circle.

CLARIFY: Talk through your health care goals with your health care provider and care circle so they understand your wishes. This will help make sure everyone knows and understands the same information.

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: Choose your health care agent. Put your wishes in writing using a health care directive.

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

Benefits of advance care planning

- It can make sure your wishes are clearly stated and communicated before a crisis or emergency.
- It increases the likelihood that the care you receive is what you prefer.
- It can reduce stress, anxiety and friction among your health care agents or those making health care decisions for you.

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. Have an advance care planning discussion. Choose your health care agent. Put your wishes in writing using a health care directive.
- Make sure your health care wishes will be available wherever you receive care at Allina Health by having your advance care plan scanned into your electronic health record. In addition, you should share copies of your plan with your health care agent, any health care providers outside of Allina Health, and other family and friends you wish.

How to begin

- Choose your health care agent. It's recommended to have a primary (main) health care agent, along with at least one alternate health care agent.
- Use this guide to prepare for a discussion with your health care agent, family members and close friends.

THINGS TO THINK ABOUT

Have you chosen a health care agent?

A health care agent is someone who has agreed to make health care decisions for you if you cannot communicate them on your own. When deciding on a health care agent, choose someone who is:

- at least 18 years old
- willing, able and available to know and understand your wishes, goals and values
- able to make decisions under stress or crisis.

It does not have to be your partner, oldest child or someone who lives near you. Your health care agent should be someone:

- whom you trust will honor your wishes, goals and values even if they are different from their own
- who is not easily intimidated by family, close friends or health care providers
- who will be an advocate for you
- who can cope with making difficult life and death decisions, including making decisions that would allow you to die.

You can choose more than one person to be your health care agent.

- It’s recommended to only have one primary health care agent. This person will be the one the health care providers will look to for advice.
- You can have one or more alternate health care agents. Your health care provider will contact these people if your primary health care agent is unavailable.
- You can choose a health care agent who lives out of state. Be sure to list current phone numbers on your cell phone, on your emergency pocket card in your purse or wallet, or in your address book. (It’s recommended to have an alternative health care agent that lives in the same state as you so that person can be at the hospital with you.)

Your health care agent will represent your wishes and make your health care decisions only if you cannot communicate them on your own.

Your health care agent will:

- make decisions about your health care, including decisions to start, stop or change treatments for you. This includes taking out or not putting in tube feedings, tests, medicine, surgery, and other decisions about treatments including mental health treatments or medicines. If treatment has already begun, your health care agent can continue or stop it based on verbal and/or written instructions.
- interpret any instructions you have made according to your health care agent’s understanding of your wishes, goals and values. (This is why the family discussion is so important.)
- review and release your medical records, health information and other personal records as needed for your health care
- arrange for your health care and treatment in any state or location he or she thinks is appropriate
- decide which health care providers and organizations provide your care and treatment.

Ask if your health care agent is willing to be your voice. Review the health care agent's roles and responsibilities. Talk with your health care agent about advance care planning using the following discussion questions. Give your health care agent a copy of your completed plan and answer any questions.

What makes your life worth living?

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.

If you have a serious illness or chronic (long-lasting) health condition, talk with your health care provider about what to expect as your illness progresses or your health condition changes. It's helpful to know what complications (problems) may happen and what treatment options may be available to you in the future.

What questions do you have for your health care provider about your health and medical conditions?

What makes life worth living to me? What does a good day look like?

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? Past experiences can be helpful such as “I don’t want to be in the same care center as Aunt Mary was” or “I loved the way Grandpa’s end-of-life care went, I hope mine is similar.” Talking about this can help your loved ones make health care decisions for you at an emotionally difficult time.

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

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)?
- At what point would you want these treatments to stop?
- What outcome would you hope for by having these treatments?

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?

For people with an illness: You will make 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 and treatments or care approaches
- 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?

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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?

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

If possible, what would your choices be for location (home, hospital, nursing home) and type of care (hospice or palliative care), organ donations and after-death arrangements?

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

HEALTH CARE DIRECTIVES

Creating a health care directive is important for you and your loved ones and trusted friends. It provides information about your health care wishes.

Members of your care circle and health care providers will use this document to interpret and understand your wishes, goals and values for future health care needs if you cannot tell them yourself at the time you are receiving care.

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 instructions 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 many different forms available for health care directives. Allina Health has three forms available for your use. There is a long form, short form and an online form.

You do not have to use a form, but your health care directive must meet the following state requirements to be valid:

- be in writing and dated
- state your name
- be signed by you or someone you authorize to sign for you
- be done when you can understand and communicate your own health care wishes
- have your signature verified by a notary public or two witnesses who are not your health care agents. (All signature dates must match your signature date.)

It should include a health care agent to make health care decisions for you when you are unable to do so. If you do not choose a health care agent, the medical staff will look to those who know you best and will follow your written document to best of their ability.

Before you prepare or revise your health care directive, you are encouraged to talk about your health care wishes with your health care providers, health care agent(s) and care circle members.

What can I put in my health care directive?

You have many choices about what to put in your health care directive. It's helpful if you include:

- a primary health care agent to make health care decisions for you
- alternate health care agents in case the first one is not available
- your health care choices based on your wishes, goals and values such as:
  - CPR (for restarting your heart and lungs if they stop)
  - ventilator or respirator (for help to breathe)
  - feeding tube (for nutrition)
  - organ donation
  - autopsy
  - where you want to receive care
  - after-death arrangements.

You can include other information in your health care directive as well. 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 health care agent must be at least 18 years old
- your health care provider cannot be your health care agent
- you cannot request health care treatment that is outside of reasonable medical practice (such as to deny comfort measures)
- you cannot request assisted suicide.

How long does a health care directive last? How often should you review your health care directive?

Your health care directive lasts until you change or cancel it.

You can change your health care directive any time. You should review your health care directive at least every 5 years or if there are:

- personal health changes (including new diagnosis or major changes)
- any change with a health care agent due to:
  - death
  - decline in health
  - divorce, separation or annulment
  - no longer willing or able.

Fill out a new document, make it valid and provide a copy to your health care provider, health care agents and anyone who has copies of your old health care directive. Ask that they destroy the old copy.

Who should get copies of my health care directive?

Give a copy of your health care directive to your health care agent, health care provider(s) (so it can be scanned into your medical record) and those who may be involved in your health care or in helping to make health care decisions for you.

POLST

POLST stands for "provider orders for life-sustaining treatment." Your health care provider uses a POLST to write medical orders indicating your health care wishes. A POLST is also for anyone who lacks capacity to make decisions or does not want resuscitation (CPR). Emergency responders (paramedics, police or firefighters) need a POLST to follow written medical orders. A POLST is a state form.

Health Care Directive	POLST
■ For anyone age 18 and older, who can make their own decisions.	■ For anyone who might die in the next 12 months, has a serious illness, who cannot make decisions, or who does not want CPR.
■ Lists your wishes, goals and values for future health care. ■ Must be witnessed or notarized to be valid.	■ Puts your wishes, goals and values into written orders. ■ Signed by your primary care provider.
■ Names at least 1 health care agent to speak on your behalf if you cannot communicate.	■ Does not name a health care agent.
■ Original document is kept in your home. ■ Give a copy to anyone you want to have one, including your primary care provider. ■ Should be scanned into your electronic health record.	■ Original document is kept in your home on the refrigerator. ■ POLST follows you from one care setting to another. ■ Should be scanned into your electronic health record. ■ If you have a health care directive: give a copy to all of your health care agents.
■ Should be reviewed at least every 5 years.	■ Should be reviewed at least every year with your health care provider.

GLOSSARY

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

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

ARTIFICIAL NUTRITION AND HYDRATION: Liquid food and fluids are given through a tube when you can no longer take them by mouth. The tube may be placed in your vein (intravenous fluids) or in your stomach (tube feeding).

CARDIOPULMONARY RESUSCITATION (CPR): A life-saving treatment used to attempt to restart your heart and lungs if they stop. CPR uses rescue breathing (someone breathing into your mouth) and chest compressions (someone pressing on your chest) to try to revive you. Also, you may need medicines and electrical shock to the heart delivered from a defibrillator machine.

CARE CIRCLE: Family, friends and others close to you who will be helping you with your care.

COMFORT-FOCUSED TREATMENT: Medical care provided with the main goal of keeping you comfortable rather than extending your life. Comfort treatments are used to relieve pain and other symptoms.

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

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

HEALTH CARE AGENT: Your health care 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.

HEALTH CARE DIRECTIVE: A legal form you complete to describe choices for future health care if you become unable to make these decisions yourself.

HOSPICE: This is care for anyone with a terminal illness who is likely to live 6 months or less if the disease runs its natural course. Hospice services may be available any place you call home. This can include your home, a hospital, or in an assisted living, skilled nursing facility, long-term care facility or residential hospice.

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

INTUBATION/INTUBATE: A tube is placed down your windpipe to help with breathing. Intubation is needed for mechanical ventilation.

MECHANICAL VENTILATION: Mechanical ventilation is used to support or replace the function of your lungs. A ventilator (or respirator) is a machine attached to a tube inserted into your mouth and then into your windpipe. It forces air into your 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.

PALLIATIVE CARE: This is care that provides relief from the symptoms, pain and stress of a serious illness. The goal is to improve quality of life for both you and your family. A care plan is created to help you live each day to the fullest and be as independent and comfortable as possible.

POLST (PROVIDER ORDER FOR LIFE SUSTAINING TREATMENT): A POLST is a state form used to write medical orders indicating your health care wishes. It's for anyone who might die in the next 12 months, has a serious illness, who cannot make decisions, or who does not want CPR.

TUBE FEEDING: Liquid food and fluids are given through a tube placed in your stomach. 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).

Trim at dotted line and keep for your records.

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, goals and values even if they are different than your own
- is not easily intimidated by family members, close friends or health care providers
- can make decisions under stress or crisis
- will be an advocate for me
- 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 decisions about my health care, including decisions to start, stop or change treatments for me. This includes taking out or not putting in tube feedings, tests, medicine, surgery, and other decisions about treatments including mental health treatments or medicines. If treatment has already begun, you can continue or stop it based on verbal and/or written instructions.

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

- Interpret any instructions based on your understanding of my wishes, goals and values.
- Review and release my medical records, health information and other personal files as needed for my health care.
- Arrange for my health care and treatment in any state or location you think is appropriate.
- Decide which health care providers and organizations provide my care and treatment.
- Make medical decisions for me and my unborn child, if I am pregnant.

If I am in the hospital, please bring a copy of my health care directive, POLST form or both when you come to the hospital.

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

Checklist

☐ understand your health situation

☐ identify your health care agent(s)

☐ have advance care planning discussions with your health care agent and health care providers

☐ complete a valid health care directive

☐ distribute copies of your health care directive to your family, health care provider and medical record. Keep track of those you give a copy to so if or when you update your document, you know who to give an updated copy.

☐ review your health care directive on a regular basis at least every 5 years.

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