

Planning for Your Future Health Care Needs



Allina Health

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Developed by Allina Health.

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This publication is for general information only and is not intended to provide specific advice or recommendations for any individual. The information it contains cannot be used to diagnose medical conditions or prescribe treatment. The information provided is designed to support, not replace, the relationship that exists between a patient and his/her existing physician.

For specific information about your health condition, please contact your health care provider.



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Future Health Care Planning

Planning Ahead

Having a chronic lung disease means that your health could get worse. Although there are no cures, there are lifestyle changes you can make to help you feel better and stay active.

It is important to plan ahead for your care as your lung disease gets worse (progresses). Having a talk with your primary care provider may not be easy. Together, you can plan what type of care may help your quality of life be what you want.

End-stage lung disease

Lung disease is described in different stages based on your symptoms and lung function (how well your lungs work). Symptoms can show up slowly. They get worse over time.

Your primary care provider will look at your lung function, how often you have flare-ups, and your need for long-term oxygen to help identify when you are near end-stage.

Severe lung disease can keep you from doing basic activities like walking, cooking and taking care of yourself.

Symptoms of end-stage lung disease can include:

- needing oxygen all the time
- needing to take steroids all the time
- having many limits on what you can physically do because you are short of breath
- having more lung infections
- losing weight
- having several hospital stays
- having symptoms even when you are resting
- being unable to leave your house
- being unable to care for yourself
- needing more care from others.

It is important to talk with your primary care provider about how your disease will get worse.

Lifestyle Changes	Treatment Choices

Advance Care Planning



Talk with members of your care circle so they understand your wishes, goals and values for future health care.

No matter what stage you are with lung disease, it is never too late to think about your future care needs.

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.

Advance care planning is a process to:

- understand your health care treatment options
- list your health care goals
- weigh your options about what kind of care and treatment you would want or do not want
- make decisions about whom you want to appoint as your health care agent and complete a health care directive
- communicate your wishes and share your health care directive with members of your care circle and primary care provider.

It is never too early to begin planning. Starting the planning process now can help you to be more in control and make informed decisions about your care. Your advance care planning conversation will change as your health changes.

Terms

- **Advance care planning** is a conversation.
- **Health care directive** is a written plan.
- **POLST** is a provider order that a health care facility and emergency providers need to carry out the plan.
- **Care circle** includes family members, friends and those who are close to you.

Having a conversation

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
- your wishes, goals and values and how they relate to your health care choices for the future.

You may share your choices with your primary care provider.

Questions to ask

Talk with members of your care circle about your wishes, values and treatment preferences for future health care needs. To help you start this conversation, here are some questions to think about with members of your care circle:

- If I were in my final months of life, how would I want to spend my time?
- What care would I want to receive?

- What would be most important: quality of life and comfort or living as long as possible no matter the burden?
- Where do I want to spend my final days of life — at home, in a nursing home or at a hospice residence?
- What would my “ideal death” look like?
- What are my thoughts on mechanical ventilation and being connected to a machine that breathes for me? If I want, how long do I want to have it? What are the chances that I would not be able to come off of the ventilator?
- If my heart stops, do I want CPR? What are my odds of survival?
- If I were unable to eat and drink on my own, would I want a feeding tube? Would I be able to eat and drink by mouth any longer?

These decisions can be difficult to talk about, but when they are discussed early and often, it will help make sure that you receive the type of care that is important to you and your family.

Health care directive

A health care directive is a written document of your health care choices. Members of your care circle and primary care providers use this to interpret and understand your wishes, goals and values for future health care needs if you cannot tell them yourself.

You do not need an attorney to fill out a health care directive. You can change your health care directive at any time.

This is a good place to list your health care agent(s), what kind of care you do and do not want, your wishes about the quality and length of your life, and what you want for treatment (including pain control).

Your health care directive can include:

- a 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 for:
 - 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
- funeral arrangements.



You can have both a health care directive and a POLST. Either or both should be scanned into your electronic health record.



You can have both a health care directive and a POLST. Either or both should be scanned into your electronic health record. Give copies of both documents to your health care agent(s).

Tip

If you live at home, keep the original yellow POLST form on the refrigerator where emergency responders can find it.

You may include other information in your health care directive.

It is important to ask someone to make health care decisions for you if you cannot make them on your own. This person is called a health care agent. Your health care agent should be:

- 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.

Ask this person if they agree to be your health care agent.

This person is not a “financial power of attorney.”

They cannot make decisions about your money or property.

POLST

POLST stands for “provider orders for life-sustaining treatment.” Your primary care provider uses a POLST to write medical orders indicating your health care wishes.

The POLST allows you to make advance decisions about life-sustaining treatment. Your primary care provider signs the POLST.

The bright yellow form guides the health care team and Emergency Medical Services on your:

- treatment goals
- preferences at the end of life
- goals during hospital stays.

One decision you can make is whether or not you want CPR if your heart or breathing stops.

The POLST stays with you if you are transferred between care settings. This includes the hospital, home or a long-term care facility.

If you have a medical crisis at home, emergency responders (paramedics, police or firefighters) will need to see the signed POLST. This is how they know your wishes, including if you do not want CPR.

If you are out in public and your heart and breathing stop, emergency responders will attempt to give you CPR.

Resources

- your primary care provider
- allinahealth.org/hcd (health care directive)
- polst.org

Health Care Directive	POLST (Provider Orders for Life-Sustaining Treatment)
■ 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.

Palliative Care

Tip

Palliative care focuses on treating symptoms and emotional and spiritual concerns. It helps you and your family understand your illness and treatment choices.

Living each day to the fullest may be important to you. Palliative care can help you be as independent and comfortable as possible.

Palliative care is for anyone who is in any stage of an advanced illness. 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.

It can help you and your family understand your lung disease and treatment choices, as well as address financial and community resource options.

This care is tailored to the needs of the patient and family. Care team members include:

- your personal doctor
- palliative care nurse clinician
- social worker
- spiritual care coordinator
- care team members in health care settings
- palliative care doctor.

This team helps you and your family members make informed health care decisions that are consistent with your beliefs, values and goals. This covers emotional, social and spiritual needs.

You may receive the highest quality of care at home, in the clinic or hospital, or in other types of care settings. You and your family have telephone access to a palliative care nurse 24 hours a day.

Palliative care may decrease the number of times you have hospital stays and it may help you avoid unnecessary Emergency Department visits.

Resources for palliative care

- your primary care provider
- allinahealth.org
- Allina Health Palliative Care (call 651-635-9173, or 1-800-261-0879 if you live outside the Twin Cities metro area)

Hospice Care

Tip

Hospice care focuses on your comfort and quality of life when your primary care provider believes you have 6 months or less to live.

Hospice keeps you comfortable and not suffering while “nature takes its course.”

You and your family may find peace of mind knowing that end-stage lung disease can be managed and treated in home, a hospital, or in an assisted living, skilled nursing facility, long-term care facility or residential hospice.

Hospice care is a special way of caring for you, your family and your caregivers if you have 6 months or less to live. Hospice focuses on your comfort and quality of life while treating your physical, emotional and spiritual needs. The focus is on comfort and providing the highest quality of life possible.

Only medicines and actions to make you more comfortable are used or added. Dying is not hurried or delayed.

Allina Health Hospice care includes the following:

- visits from specially trained staff
- medicines related to your disease and those needed for comfort
- medical equipment and supplies to support your care such as hospital beds, wheelchairs, oxygen, wound supplies and products to help with bladder control.

Your hospice health care team includes:

- nurses
- home health aides
- social workers
- chaplains
- music and massage therapists
- volunteers
- grief counselors
- pharmacist.

Resources for hospice care

- your primary care provider
- allinahealth.org/hospice
- Allina Health Hospice (call 612-262-2200 or 1-855-227-5111).

To Do List



☐ Advance care planning:

- ☐ Talk with members of your care circle about your wishes, values and goals for future health care.
- ☐ Fill out a health care directive.
 - Go to allinahealth.org/hcd and print a blank copy. Or, fill out an electronic version by creating an Allina Health account.
 - Name at least one health care agent. Ask this person if they agree to be your health care agent.
 - Write down your preferences and make choices for your future health care.
 - Have your directive notarized or witnessed.
 - Give copies of your directive to anyone whom you would like to have it. (Keep the original somewhere handy.)
 - Give a copy to your primary care provider so it can be scanned into your electronic medical record.
 - If you already have a directive, review it to make sure it still conveys your wishes, values and goals. Ask your health care agent if they are still willing to serve in that capacity.
- ☐ Ask your primary care provider about a POLST if you are interested.

☐ Palliative care:

- ☐ Ask your primary care provider about a palliative care consult.
- ☐ Go to allinahealth.org or call 651-635-9173 to talk with a nurse about your options.

☐ Hospice care:

- ☐ Ask your primary care provider about a hospice consult.
- ☐ Go to allinahealth.org or call 612-262-2200 to learn more.

Questions and Notes

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allinahealth.org