

# YOUR CARE, YOUR CHOICES

Advance Care Planning Conversation Guide



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# What is Advance Care Planning?

## Being Prepared is Important

Living in Alaska, we spend a lot of time getting prepared. We prepare for fishing, hunting, weather, winter, school and travel. Being prepared is important because it helps us to plan for the things that may or may not happen—just in case. Thoughtful and careful preparation helps protect us; it also gives peace of mind to us and our families. The same is true when planning for medical care.

This conversation guide can be used to learn about Advance Care Planning, and as a talking tool for you, your family and health care providers. This conversation guide is not to be used as legal advice in any situation. You are empowered to make your own health care choices. Living life to the fullest can mean different things to different people, and it is important to think and talk about what it means to you.

The stories on the next three pages can be used to help you think and talk about what life means to you in the event that you became seriously ill or badly hurt. Although the stories are made up and do not represent real people, these are common health care situations where Advance Care Planning can help you be prepared.

Advance Care Planning is one way to be prepared for the unexpected. Advance Care Planning lets your family, friends and health care team know how you wish to be cared for if you ever become seriously ill or badly hurt.

- **What does Advance Care Planning mean to you?**
- **How could Advance Care Planning be helpful for you and your family?**
- **Do the people who are important to you know your health care wishes?**

**"One must be wise in knowing what to prepare for and equally wise in being prepared for the unknowable."**

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by James H. and Robin Barker

# Be Prepared for the Unexpected

David was a big, strong and healthy man, who thrived in the community where he was born. He was always busy hunting, fishing and enjoying nature. David loved his family, church and community. He would help anyone in need. One day, David and his brother went fishing. During the long boat ride, David did not see a log hidden just under the surface of the water until it was too late. The boat hit the log going full speed, knocking David off his feet and slamming him into the side of the boat.

David woke up lying in the bottom of the boat, bleeding from a cut on his head. His brother was crouched over him, calling his name. He told his brother he had a really bad headache.

David's brother drove the boat quickly back to land and brought him to the clinic for a checkup. While the health aide was stitching up his head,

David started to have a seizure and wouldn't wake up. The health aide called for an emergency paramedic, but on the way to the hospital David stopped breathing. A breathing tube was put into David's windpipe.

David was rushed to the hospital for tests and was connected to a machine to help him breathe. One test showed massive bleeding in his brain. Doctors told David's family members that they didn't think he would survive his injury. They said if he did recover, he probably would not know himself or his family. He would likely need around the clock care that would make it impossible for him to live at home again and he would need a feeding tube to keep him alive.

David's family was stunned. They didn't know what to do. They loved him very much, but didn't want him to suffer.

**If you had an accident and weren't expected to wake up, what would you want your family and your health care team to do?**

# Be Prepared for the Journey

Mary was diagnosed with colon cancer two years ago and had surgery to remove the tumor. During a checkup for a cold that wouldn't go away, doctors found the cancer had come back and spread into her lungs. Mary was told by the oncologist that there was no cure.

Mary thought about her father, who died of cancer five years earlier. He traveled back and forth to Anchorage for cancer treatments. One day, her father made the decision to stop cancer treatment and stay at home with his family even though he knew his decision might shorten his life.

At the time, Mary was so angry at her father! She felt like he was giving up. He gathered the family together and spoke quietly.

"I'm tired of all of this," he said. "I just want to be home with my grandkids. Sleeping in my own bed, eating my Native food and keeping my own

schedule. I don't want to spend the rest of my life going to doctor appointments. I have a life left to live. I don't want to waste so much of my time and energy and be too sick to go home. I don't want to die in the hospital. For what? When it's my time, it's my time. This is my decision."

Mary smiled when she remembered him. He was so happy to be home snuggling with his grandkids on the couch and riding with his son to check the fishing nets. He was enjoying his life and was truly at peace with his choices. He died shortly after the holidays, but Mary was grateful for their time. It meant so much to her.

She thought about her cancer treatment and wondered how her journey would look. What was important to her? What did she want to do before she got too sick? Where did she want to be? And, more importantly, when was enough, enough?

**If you were diagnosed with an illness that couldn't be cured, but could be managed for a period of time, what would be important to you?**



# Be Prepared for the Transition

John was a respected village Elder. His culture was so important to him. He loved to dance, tell stories and teach his language and the traditional ways of his ancestors. The community depended on John for his wisdom, knowledge and position as a peacekeeper.

Sadly, John suffered from a bad heart and lungs over the past 20 years. Every year, he had more and more clinic visits. He was staying overnight at the hospital and sometimes he was in for weeks. The doctors tried to help him feel better with medicine, but John still struggled. He was having more trouble breathing. Sometimes it made him anxious. Even on short walks he had to stop and catch his breath. He was tired all the time and it seemed like he was the first to catch every cold in the village. His health worried him.

John was sad because he couldn't do the things that he loved to do anymore. He was old and he lived a good long life, but John worried about his family, his village and all the knowledge that he held. Who would watch over the village? Who would teach the ways of the Elders to the children?

One night, John's breathing was really bad. His home breathing treatments weren't helping. His wife was scared. John knew he was very sick. The last time he went to the hospital the doctor told him if he got sick again, he might need a breathing machine.

John wondered if he went to the hospital, would he ever make it back out? John loved his life and his family, but he didn't know what to do.

As you grow old and your body starts to get tired, what will be most important to you?



# What is an Advance Health Care Directive?

An Advance Health Care Directive, the form you fill out for Advance Health Care Planning, can be written or spoken. When filled-out properly, an Advance Health Care Directive becomes a legal record of your medical choices. An Advance Health Care Directive can be used to help your family and health care team get you the health care you want. An Advance Health Care Directive protects your health care rights and makes your wishes known. This workbook will guide you through an Advance Health Care Directive and help you create your own.

**There are two parts to an Advance Health Care Directive that will be explained in this booklet:**

- **Part I:** Choosing a Health Care Agent, also known as a Durable Power of Attorney for Health Care Decisions
- **Part II:** Instructions for Health Care, sometimes called a living will

**Important things to know about Advance Health Care Directives:**

- Anyone age 18 and older may fill out an Advance Health Care Directive
- Once completed, your Advance Health Care Directive should be reviewed every year to make sure it still represents your wishes
- If you need to make changes, you may make a new Advance Health Care Directive at any time

An Advance Health Care Directive is a set of medical instructions that communicates your health care wishes to your medical providers and the people who are important to you.

- **Have you ever known someone who had a serious accident or illness that left them unable to make medical decisions or speak for themselves?**
- **What was that experience like?**
- **If you were in a similar situation, would you have done anything differently?**

# PART I:

## What is a Health Care Agent?

Your Health Care Agent does not have to be a family member. They can be a close friend or neighbor. The person (or people) you choose as your Health Care Agent should be someone:

- Who knows you well and who can understand and follow your medical wishes
- Who you trust to speak as your voice
- Who can be easily reached by telephone
- Who is age 18 or older and not your health care provider or an employee of your health care provider (unless related by birth, marriage or adoption)

It is important for your Health Care Agent to be able to speak on your behalf. Your Health Care Agent should be able to answer 'yes' to these questions:

- Is he or she willing to be my health care agent?
- Does he or she fully understand my medical wishes?
- Can he or she make health care decisions for me in stressful situations, even if my medical wishes may be different than his or hers?

Consider choosing a different person as your Health Care Agent if they answered 'no' to any of these questions or if they seem uncomfortable talking about your health care decisions.

A Health Care Agent is someone who will tell your story if you cannot. This person is able to make health care decisions for you based on what they know is important to you. You may choose one or more Health Care Agents. Some questions to ask when thinking about choosing your Health Care Agent:

- **Who knows you well?**
- **Who can you trust to make your health care decisions even if they disagree with your wishes?**
- **How does this person handle stressful situations?**

Choose your Health Care Agent(s) on [page 1](#) of the Advance Health Care Directive

# PART II: What are Instructions for Health Care?

When completed, Instructions for Health Care, also known as a living will, can:

- Protect your health care rights
- Make your health care wishes known
- Shelter your family from the burden of making difficult medical treatment decisions
- Help your health care team treat you in the best possible way according to your personal values, health care goals and wishes

Instructions for Health Care document personal preferences about quality of life as well as medical treatments.

## Quality of life

Quality of life means different things to different people. The experiences, stories and culture of every person help define what is important to them. For some people, quality is measured by feeling well and being independent. For others, every minute of life is important, no matter how they feel or what needs to be done to extend their life. It is also important to share where they spend their last days of life and how they are cared for in their last days. How they wish to honor their body after death may be important and very personal choice.

Instructions for Health Care are specific directions about medical treatments that you may or may not want if you are unable to speak for yourself. Some questions to ask when thinking about your Instructions for Health Care:

- **What does quality of life mean to you?**
- **What brings you joy and makes your life worth living?**
- **Is there anything special you want your family and friends to know?**

Make choices according to your health care goals, values and preferences on pages 2 and 3 of the Advance Health Care Directive



# What is Cardiopulmonary Resuscitation?

Cardiopulmonary Resuscitation (CPR) can be life saving for some people when their heart or breathing stops, such as in the event of cold water drowning, electrocution or sudden heart attack. CPR is used to keep blood moving to the heart, lungs, brain and other vital organs. CPR includes chest compressions, mouth-to-mouth or artificial breathing, medications and, in some cases, electrical shocks.

## CPR works best when:

- You are young and healthy
- It is initiated within a few minutes of the event
- Whatever caused the event can be reversed or cured

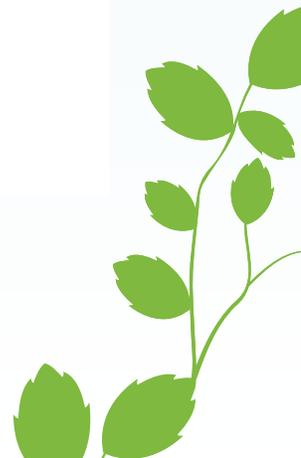
## CPR does not work well if:

- You have chronic health problems
- You have a disease or illness that cannot be cured
- Your body is weak

If you receive CPR, you will most likely need to be sent to a hospital that has advanced medical services, such as an intensive care unit. CPR can lead to the need for a breathing machine, critical care or long hospital stay. Serious side effects may include brain damage, rib fractures and/or organ injury. Even when given to a healthy person, CPR does not always work.

CPR is a medical procedure used when a person's heart or breathing stops. Some questions to ask when thinking about CPR:

- **How successful is CPR?**
- **Do you know someone who has had CPR?**
- **How do you think CPR could meet your health care goals?**



# What is Life Support?

Life support treatments include any medical test, blood product, surgery, procedure, machine and/or medicine needed to help prolong life. Life support is often given in advanced hospital settings, like the intensive care unit. Sometimes a trial of life support is useful to see if your body can get stronger; however, each treatment has risks. Life support does not work well if your body is weak and shutting down due to chronic health problems or if you are dying. Clear communication with your Health Care Agent will help your doctors treat you the best way possible according to your personal values, health care goals and wishes. If you choose not to have life support treatments, your health care team will still continue to provide medical care. This medical care will include medical treatments focused on providing comfort.

## Common forms of life support:

**Mechanical ventilation** — A machine, called a ventilator, that breathes for you so oxygen can move through your lungs. Mechanical ventilation is used when you are intubated.

**Intubation** — A tube in your windpipe that allows a ventilator to breathe for you if you cannot breathe by yourself. Medicines are often needed to keep you still and asleep for safety while you are intubated. You will not be able to eat or talk while intubated. Surgery for a permanent tube in your neck may be needed if you are on mechanical ventilation for a long period of time.

**Dialysis** — Treatment used when your kidneys are not working and cannot balance the water and waste in your blood. A dialysis machine is used to clean your blood and remove wastes.

**Vasopressors** — Medicines used to increase blood pressure. When blood pressure gets too low, vital organs do not get the oxygen they need to survive. Vasopressors are given temporarily to improve blood pressure.

**Antibiotics** — Medicines that help fight infection. During a critical illness, antibiotics may need to be given directly into the blood stream through an IV.

**Blood products** — Given if your blood counts go too low due to sickness or bleeding from an injury. Blood products include red blood cells, platelets and other important things that are needed to transport oxygen and help stop bleeding. Blood products are often donated by other people and are put directly in the blood stream through an IV.

Life support is medical treatments used to maintain life when one or more vital organs shut down. Some questions to ask when thinking about life support:

- **Have you ever known someone who needed life support?**
- **What was that like?**
- **Is there ever a time when you would not want life support?**

# What is Artificial Nutrition?

If there comes a time when you are not able to speak for yourself and you cannot eat or drink safely, artificial nutrition may be used to keep you alive. Artificial nutrition can be given through a tube into your stomach (through the nose or surgically inserted), intestines or vein. Receiving artificial nutrition through a permanent feeding tube can extend life for some, but may be harmful for others. Artificial nutrition may have side effects including bloating, swelling, diarrhea and an increased risk for infections such as pneumonia.

Artificial nutrition work best when:

- It is needed for a short time to help recover from a surgery, injury or sudden illness
- You have lost your ability to swallow due to an illness

Artificial nutrition does not work well and may be harmful when:

- You have chronic health problems and are nearing the end of life
- You have a non-curable cancer or advanced dementia

Artificial nutrition is liquid food given through a tube down the nose, into the stomach, intestines or vein. It can be given to sustain life for short periods as someone gets better or for longer periods for someone who may never get better. Some questions to ask when thinking about artificial food and fluids:

- **Do you know anyone who has needed artificial nutrition?**
- **What was that like?**
- **Is there ever a time when you would not want artificial nutrition?**

Make choices about artificial food and fluids on [page 4](#) of the Advance Health Care Directive



# How do I Make My Advance Health Care Directive Legal?

An Advance Health Care Directive is recognized as a legal document in the State of Alaska when properly signed. An Advance Health Care Directive can be either witnessed or notarized.

When using two witnesses to legalize your Advance Health Care Directive:

- Both witnesses must be least age 18 or older
- Neither witness can be your Health Care Agent
- Neither witness can be your health care provider or an employee of your health care provider/clinic

AND

- At least one of the witnesses cannot be related by blood, marriage or adoption
- At least one of the witnesses cannot be a beneficiary of your money, property, shares or permits

When using a Notary Public to legalize your Advance Health Care Directive:

- Do not sign your Advance Health Care Directive until you are told to do so by the Notary Public
- Be prepared to show identification

When you are ready, you can complete an Advance Health Care Directive. After it is filled out, signed and witnessed, it will become legally recognized in the State of Alaska. Some questions to ask after completing your Advance Health Care Directive:

- **Who should have copies of your Advance Health Care Directive?**
- **Where should you keep the original copy of your Advance Health Care Directive?**
- **What if you want to make changes to your Advance Health Care Directive?**

Legalize your Advance Health Care Directive by signing [page 5](#) of the Advance Health Care Directive with two witnesses or a Notary Public

# How do I Share My Wishes with Others?

- Talk to your family and friends about your choices and wishes
- Fill out an Advance Health Care Directive (ask your health care provider for help if needed)
- Sign your Advance Health Care Directive in front of two witnesses or a Notary Public to make it legal
- Give a copy of your Advance Health Care Directive to your Health Care Agent(s) and health care provider(s)
- Keep a copy of your Advance Health Care Directive at home in a safe place where it is easy to find
- Take a copy of your Advance Health Care Directive with you when you travel for medical treatment
- Cut out the wallet card below and keep it with you so that others will know about your Advance Health Care Directive
- Look at your Advance Health Care Directive often to make sure it is still your wishes. Make a new one if there are changes. If you make changes, make sure to tell your Health Care Agent(s) and give new copies to your health care provider(s)

I have given these people a copy of my completed Advance Health Care Directive:

Names

Phone numbers

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I have an Advance Health Care Directive _____ Signature Please read these documents and/or discuss my wishes with my Health Care Agent (listed below) in an emergency. Name: _____ Address: _____ Phone: _____	My primary care provider is: Name: _____ Address: _____ Phone: _____ I have put my original Advance Health Care Directive here: _____ _____ _____
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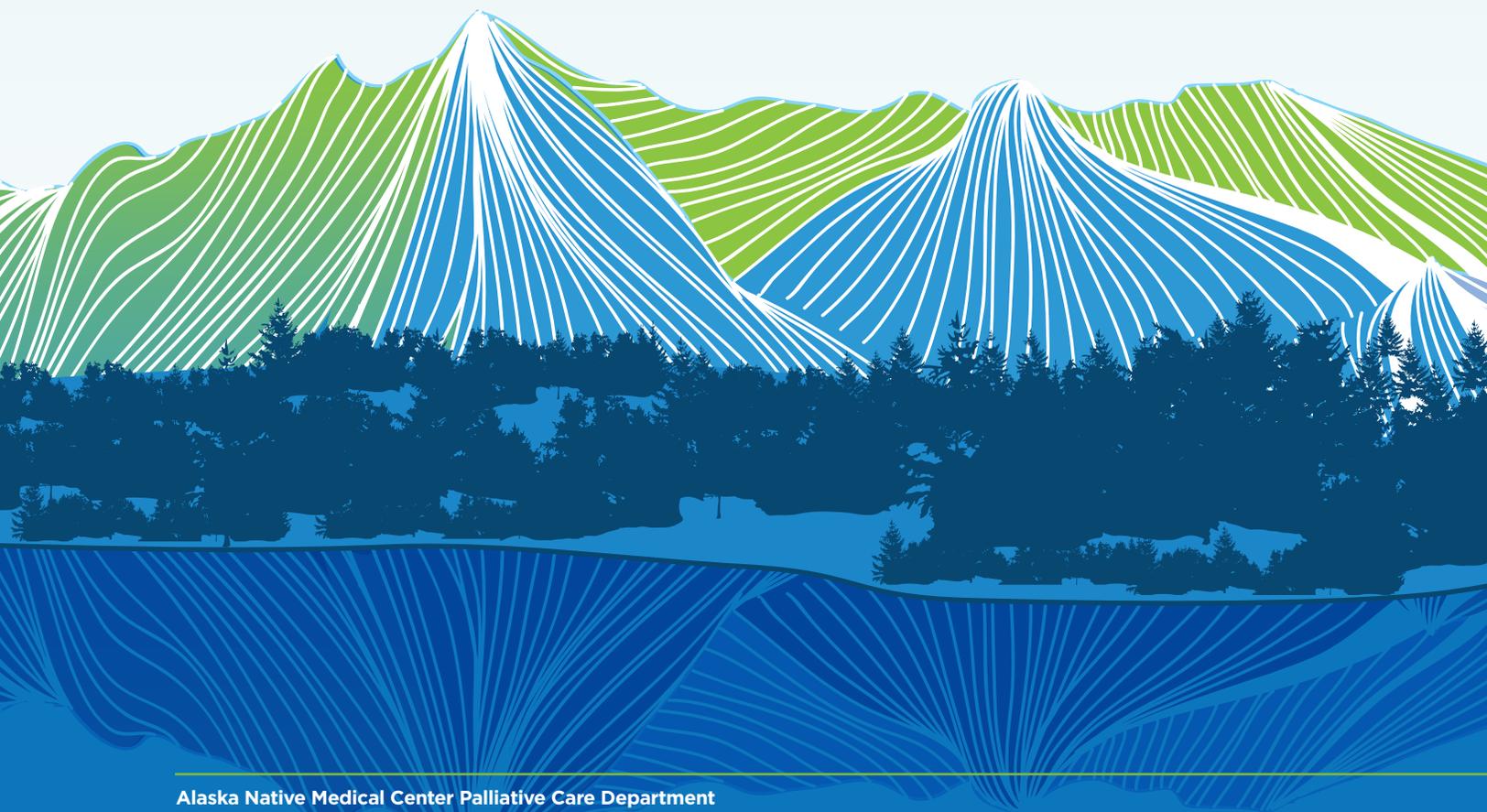


# Know Your Rights

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Your rights to your health care and choices are supported by state and federal laws.

- You have a right to have your wishes respected and to be treated with dignity
- You have a right to know about your health condition
- You have a right to know about your treatment options, including the risks and benefits of treatment
- You have a right to say yes or no to any or all medical tests or treatments
- You have a right to have your pain and symptoms treated
- You have a right to make an Advance Health Care Directive



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The Alaska Native Tribal Health Consortium and Southcentral Foundation jointly own and manage the Alaska Native Medical Center under the terms of Public Law 105-83. These parent organizations have established a Joint Operating Board to ensure unified operation of health services provided by the Medical Center.