My Advance Care Plan & Guide for Native Americans

Plan the healthcare you want in the future and for the end of your life

Name

Date

National Indigenous Elder Justice Initiative
We like to think that we will always be healthy and able to make decisions for ourselves. But if you develop a sudden illness or serious condition or are involved in an accident, you might not be able to make decisions for yourself.

Making your wishes known while you are still healthy is a good idea. Sharing your healthcare decisions with others is the best way to make sure your decisions are respected.

Your family and loved ones will benefit from your advance planning. Knowing your wishes will help ease their burden and reduce their uncertainty if they ever have to make medical decisions on your behalf.

In this booklet, you will learn about the types of decisions you can make ahead of time and how to let others know what you want.

We are thankful to have received permission to adopt this document from the My Advance Care Plan & Guide developed by the Maori, the Indigenous people of Aotearoa (New Zealand).

We would also like to thank the Indigenous Elders from the U.S. who offered their input in this adaptation.

The Center for Rural Health, at the University of North Dakota School of Medicine & Health Sciences, houses the National Indigenous Elder Justice Initiative.

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This document is an advance care plan. Completing it will help you and your family think and talk about your wishes for your healthcare and end of life planning.

**If you do complete an advance care plan, please:**
- Discuss it with your family and caregivers
- Share it with your healthcare team
- Make copies for people who can help make sure your wishes are respected
- Review this plan on a regular basis

Section 5 of this advance care plan references making a spiritual journey or death. If you are uncomfortable, feel free to skip pages 11 and 12.

As I work through this plan, these are the questions I have and the things I need to know:

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________
1. My Advance Care Plan

An advance care plan describes what is important to you as well as the healthcare and treatments you want.

You and your healthcare team can work together to make an advance care plan. This plan will help the healthcare team caring for you, your family, and loved ones make decisions about your care if you can no longer tell them what you want.

This advance care plan is yours.

You can show it to anyone involved in your healthcare and give a copy of it to your family and loved ones.

You can add to your plan as often as you like and change your decisions at any time. It is important to share any changes you make with the people who have a previous copy of your plan.

You do not need to complete every section. However the more you complete the easier it will be for family and your provider to respect your wishes.

This guide will help you think and talk about:
• What is important to you now
• How you like to make decisions
• What care and treatment you would like in the future
• What is important to you after your death

This is my advance care plan and contains my choices. Please follow this plan if I am unable to tell you what I want.

Last Name

First Name

Date of birth

Tribe/Band/Clan

Address

City    State    Zip Code

Phone

Mobile
Here are some questions to help you work out what matters to you:

• What makes you happy?
• What brings you pleasure and joy?
• How do you like to spend your time?
• What are your hobbies and interests?
• Are there routines you really like, for example, how do you like to start or end your day?
• What makes each day meaningful?
• Who do you like spending time with?
• Do you have cultural, religious, spiritual rituals, or beliefs?

Here are some other things that might be important or meaningful to you:

• Being able to talk to and be close to people
• Being aware of who and where you are
• Being able to feel the love and concern of others
• Being able to live a life that is meaningful
• Being close to a pet
• Being able to attend to your spirituality or religion
• Being part of your culture
• Being able to contribute to society
• Being hugged or having your hand held
• Being able to walk and/or move around by yourself

This is what I want my family, loved ones, and healthcare team to know about who I am and what matters to me:


My cultural, religious and spiritual values, rituals and beliefs:


To honor these beliefs, I want my family, loved ones, and healthcare team to:
2. What Worries Me

Are there things that worry you when you think of your future?

**For example, do you worry about:**

- How your health might affect your future plans
- How your health might affect your loved ones
- Where you will be cared for
- How you will manage pain if it occurs
- Being unable to communicate
- Being a burden
- Going into care
- Dying alone
- How your family and loved ones will manage without you
- Being stuck in bed
- Your family or loved ones over-riding your wishes
- A clash between traditional and modern cultural ways
- Finances

This is what I want my family, loved ones, and healthcare team to know about what worries me.

I worry about:

- my loved ones because:
  -
  -
  -

- suffering, to me this means:
  -
  -
  -

- not being able to talk or communicate

- not doing things such as:
  -
  -
  -

- other things that worry me are:
  -
  -
  -

- nothing worries me
3. Why I’m Making An Advance Care Plan

Some things to think about:

• What illnesses have your family had, and could that happen to you
• Does your health stop you doing some day-to-day activities
• Do you have any health conditions you are getting care or treatment for

Talk to your doctor or healthcare team to help you understand what impact your current and future health might have.

You may need to discuss the following:

Could your illness change:

• How you live your life
• How independent you are
• What you need to plan for

What might your illness mean for the people who may need to care for you?

This is why I am making My Advance Care Plan:

☐ I am well
☐ I am receiving care and treatment for the following:

☐ I understand this may happen to my health in the future:
3. Why I’m Making An Advance Care Plan

Facing my future makes me think about:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Facing my future makes me feel:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

If my time were limited, my priorities would be:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
**4. How I Make Decisions**

Think about the decisions you might need to make about your health.

Think about how you like to make decisions. Do you need time? Do you like lots of information and options, or do you prefer to let others decide?

Sometimes you might be faced with having to make a healthcare decision in a crisis (such as an accident or when you are really sick). This can be made easier for you if you have already thought about how you like to make decisions and who you want involved.

**Who can make decisions on your behalf when you are unable to?**

If you are too unwell to speak for yourself, others will need to help make the decisions for you. Talk to them about what matters to you and what you want or don’t want to happen, while you still can.

If you want a person to have the power to make decisions for you, consider appointing them as your enduring power of attorney (EPOA) for personal care and well being. This means they can be involved in most decisions about your care. This person will not make decisions for you unless you can no longer decide for yourself.

For more information, contact an attorney, your tribe, or legal-aid through tribal offices.

There is no right or wrong answer for the following questions, as each depends on your needs and desires. Mark anywhere in the scale, for each prompt, to indicate for others what it is that you want.

<table>
<thead>
<tr>
<th>I like to know...</th>
<th>basic information but not the details</th>
<th>all the details about my condition and my treatment</th>
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<tbody>
<tr>
<td>only the basics</td>
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<table>
<thead>
<tr>
<th>As doctors treat me, I would like...</th>
<th>to have a say in every decision</th>
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<tbody>
<tr>
<td>my doctors to do what they think best</td>
<td></td>
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<tr>
<td>shared decision making with my doctors</td>
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</table>

<table>
<thead>
<tr>
<th>If I have an illness that will shorten my life, I prefer to...</th>
<th>not know how quickly it is likely to progress</th>
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<tbody>
<tr>
<td>know my doctor’s best estimate for how long I have to live</td>
<td>know what stages to expect</td>
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<table>
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<tr>
<th>How involved do you want your loved ones to be?</th>
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<tbody>
<tr>
<td>I want them to do exactly as I have said, even if it makes them uncomfortable</td>
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<table>
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<tr>
<th>When it comes to sharing information...</th>
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<tbody>
<tr>
<td>I don’t want my loved ones to know anything about my health</td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>I am comfortable with my loved ones knowing everything about my health</th>
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</thead>
</table>
4. How I Make Decisions

If you appoint an enduring power of attorney (EPOA) for personal care and well being, include them in any discussions about your future care and treatment options.

Talk them through your advance care plan and give them a copy.

If you do not have an EPOA, it is a good idea to name someone to help your healthcare team make the best decisions for you.

Talk to this person about what is important to you and how you feel.

For both your enduring power of attorney for personal care and well being, or your nominated person, choose someone who:
• Knows you well
• Cares about what is important to you
• Helps you without taking over
• Listens to you and is respectful
• Will tell people about your wishes and try to make sure they happen

When I am unable to make decisions, I would prefer them to be made like this:

- I want my enduring power of attorney (EPOA) for personal care and well-being to make decisions using the information in this advance care plan.

  My EPOA’s name is ________________________________

  Relationship to me ____________________ Phone ______________________

- I don’t have an EPOA.
  Using the information in this advance care plan, the following person will help my healthcare team make the best decisions for me.

  Name ________________________________

  Relationship to me ____________________ Phone ______________________

In addition, the following people know me well and understand what is important to me. I would like them included in discussions about my care and treatment.

Name ________________________________

Relationship to me ____________________ Phone ______________________

Name ________________________________

Relationship to me ____________________ Phone ______________________
5. When I Start My Journey

When you are starting your journey, you will be made comfortable. The dying process is different for everyone and will be affected by your age, general health, or illnesses and can happen very quickly, or it may take several days.

For example, you might need:
• Pain-relieving medicines and treatments
• Medication to ease breathing difficulties
• Medication to manage nausea

Consider what quality of life may mean to you at this stage of your life:
• Being aware and thinking for yourself
• Communicating with the people who are important to you

What do you think will be important to you as you start your journey:
• When you are close to passing, what do you want or not want?
• When you think about dying, what situations worry you?
• Who do you want with you as you die?
• What would your ideal passing look like?
• What kind of spiritual care do you want at the end of your life?

As I journey on, my quality of life means:

Other details I would like you to know:

I understand that when I am dying my comfort and dignity will always be looked after.

This will include food and drink if I am able to have them.

In addition, I would like you to:

- let the people who are important to me be with me
- take out things, like tubes, that don’t add to my comfort
- stop medications and treatments that don’t add to my comfort
- attend to my religious, cultural and/or spiritual needs, as I described in section 2
5. When I Start My Journey

Where would you like to spend your last few weeks or days?
- What would be needed for this to happen

_As I start my journey, I would prefer to be cared for:_
- Where do you keep their contact details
- Who knows to do this for you

If your condition meant you couldn’t be cared for in your preferred place, where else might you like to be?

What things would be important?
For example, having my loved ones around, maintaining my privacy, etc.

The place I die is important to me:  ○ Yes  ○ No

When I am dying, I would prefer to be cared for:
- at home, which for me is:

- in a hospital
- in a hospital level care facility (residential care)
- in hospice
- I don’t mind where I am cared for

Other details I would like you to know:

- [Blank line]
- [Blank line]
- [Blank line]
6. My Treatment And Care Choices

This section is best completed with help from a doctor, nurse, or specialist.

There are medical procedures that keep you alive or delay death. These may include resuscitation (CPR), life support, getting food and drink through a tube, and kidney dialysis.

Sometimes treatments can be both helpful and harmful. They may keep you alive, but not conscious, or make you a bit better for a short time but cause you pain.

You need to decide if this is what you want. Your healthcare team will only offer treatments that you will benefit from, this includes the offer of CPR.

Think about what is important to you. For example, quality of life (how good your life is) or quantity of life (how long your life is)?

Are there circumstances in which you would want to stop being kept alive and be made comfortable so you can have a natural death?

If I am seriously ill and I am unable to make decisions for myself, the following best describes the care I would like to receive. I understand this does not require the healthcare team to provide treatments which will not be of benefit to me.

Seriously ill to me means: ___________________________________________

Choose only ONE of these five options.

1. If required and appropriate, I would want CPR to be attempted:
   - [ ] YES
   - [ ] NO
   - [ ] I will let my doctor decide at the time.

2. I would like my treatment to focus on quality of life. If my health deteriorated, I would like to be assessed and given any tests and treatments that may help me to recover and regain my quality of life, but I DO NOT WANT TO BE RESUSCITATED.
   For me, quality of life is: __________________________________________

3. I would like to receive only those treatments, which look after my comfort and dignity rather than treatments, which try to prolong my life. I DO NOT WANT TO BE RESUSCITATED.

4. I cannot decide at this point. I would like the healthcare team caring for me to make decisions on my behalf at the time, taking into account what matters to me and in close consultation with the people I have listed in Section 4.

5. None of these represent my wishes. What I want is recorded in my advance directive on page 14.

I choose option number: ________

13

If you have treatment and care preferences for specific circumstances or you want an advance directive, please write the details below.

An advance directive is a way of choosing beforehand specific treatments you would or would not want in different circumstances if you were no longer able to speak for yourself.

If you can’t speak for yourself, it is the responsibility of your healthcare team to apply your advance care plan and any advance directive.

**When applying the advance directive, they must be confident that you:**

1. fully understood what you were asking for
2. were free from influence or duress from someone else
3. meant this to apply to the current situation

<table>
<thead>
<tr>
<th>In the following circumstances:</th>
<th>I would like my care to focus on:</th>
<th>I would accept the following treatments:</th>
<th>I would wish to refuse or stop the following treatment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Severe stroke, unable to recognize anyone</td>
<td>Example: Allowing a natural death</td>
<td>Example: Comfort measures</td>
<td>Example: Artificial feeding</td>
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If I have left this section blank, I am happy with the choice I made on the previous page and have no other preferences.
6. Signatures

Your healthcare team has a responsibility to follow your wishes. Signing this section is optional, but it helps show your healthcare team you fully understand what you are stating. The doctor leading your care will be more confident about using your plan if you sign and date it.

The healthcare professional who helped you complete your plan is also asked to sign it and provide their details.

Remember to share copies of your completed plan with your primary care provider, nurse or specialist, your enduring power of attorney for personal care and welfare or your nominated spokesperson and important family and loved ones.

Your rights:

- Advance directives and advance care plans do not need to be formal, written documents?
- They can include any treatments, not just life sustaining treatments?
- If a healthcare provider violated this right, they would be guilty of a criminal offense?
- A person cannot demand a specific treatment or ask for anything that is illegal?

By signing below, I confirm:

- I understand this is a record of my preferences to guide my healthcare team in providing appropriate care for me when I am unable to speak for myself.
- I understand treatments that would not benefit me will not be provided even if I have specifically asked for them.
- I agree that this advance care plan can be in electronic format and will be made available to all healthcare providers caring for me.

Name

Address

Phone Signature Date

The healthcare professional who assisted me

By signing below, the healthcare professional confirms that:

- I am competent at the time I created this advance care plan.
- We discussed my health and the care choices I might face.
- I have made my advance care plan with adequate information.
- I made the choices in my advance care plan voluntarily.

Healthcare Practitioner

Facility/organization

Designation

Phone Signature Date
7. After My Death

Have you considered organ and tissue donation?

Donated organs and tissues can help others to live and to have an improved quality of life. For further information go to: www.organdonor.gov.

Have you considered leaving your body to medical science?

There are specific processes and forms that need to be completed. For further information, contact a local university medical school.

Do you have any body parts that need to be returned to you?

Immediately after death or in the time between death and your funeral, are there any ceremonies or rituals you would like performed?

Is it important where your body is kept?

For your funeral or farewell:

• Do you have preferences for your obituary/death announcement?
• Do you have any ideas or preferences for your funeral or farewell?
• Do you already have a prepaid funeral or life celebration plan. If so, with who?
• Are there songs you would like sung or things you wish people to know?

My wishes for organ and tissue donation:

________________________________________________________________________

My wishes for caring for my body immediately after death.

After I die I would like to be:  ○ Buried  ○ Cremated

For my funeral or burial/potluck/wake, I would like:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

I would like my last resting place to be:

________________________________________________________________________

This is important to me because:

________________________________________________________________________

I don’t mind. I would like the decision to be made by:

________________________________________________________________________
7. After My Passing

**Final questions to think about.**

Is there anything important you want your family and loved ones to know?

Are there any financial records or bank account details that need to be managed?

Have you thought about your social media or Facebook accounts and how these should be managed?

In the years after your passing, are there ways you would like to be remembered?

Do you have any final words for your loved ones?

We recommend everyone has a will. If you have a will, who is it with? If you need advice on making a will, go to an attorney, your tribe or tribal office legal aid.

Be sure to print out a copy for your home file. Remember to share with your healthcare team and loved ones.

**Things I would like my loved ones to know:**

<table>
<thead>
<tr>
<th>Document/item</th>
<th>Where it is</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>My will</td>
<td></td>
<td></td>
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</table>

To save My Advance Care Plan on your own computer, CLICK SAVE (if the save button does not function then using your mouse, right-click and select Save As). When the dialog box opens type in the name of this document.