



My Advance Care Plan & Guide for Native Americans and Other Resources

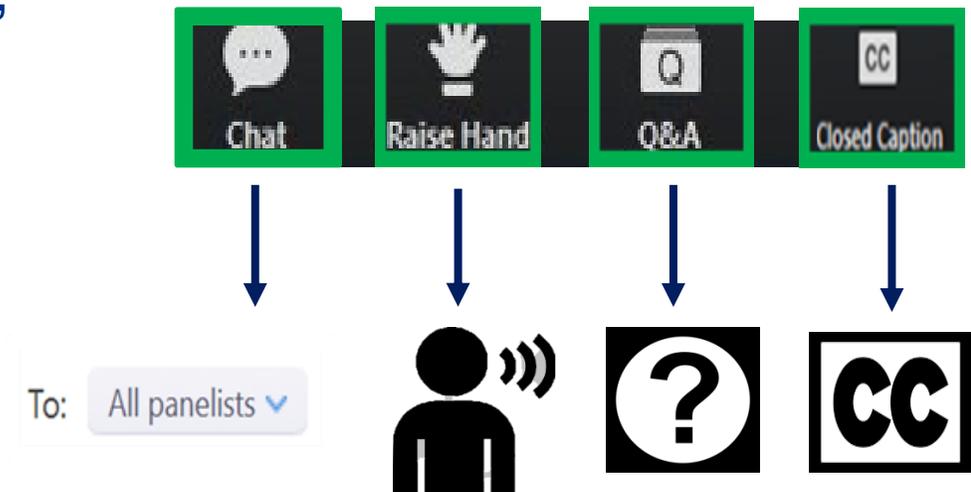
April 26, 2023

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Enjoy the session!





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Webinar Objectives

- Discuss the benefits of an advance care plan
- Use an advance care plan to address the needs of American Indians, Alaska Natives, and Native Hawaiians

Today's Presenters



Bill Benson
President
International Association for
Indigenous Aging



Peggy Jo Archer
Project Coordinator
International Association for
Indigenous Aging



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

Welcome to the Native American Elder Justice Initiative (NAEJI) National Resource Center!

My Advance Care Plan & Guide for Native Americans

Land Acknowledgment

We want to take a few moments of silence to acknowledge the land we are on. We acknowledge with gratitude the Native peoples on whose ancestral homelands we are residing, as well as the diverse and vibrant Native communities who make their home here today.

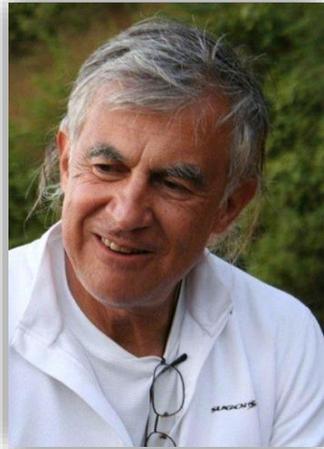
Who We Are

Founders



Bill Benson

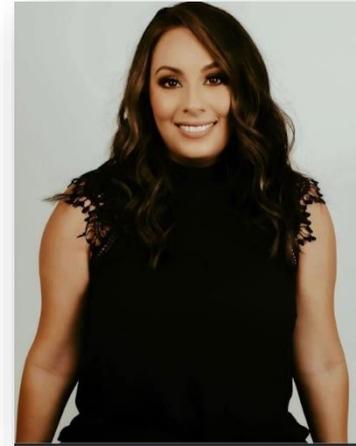
President
IA²



Dave Baldrige
(Cherokee)

Executive Director
IA²

NAEJI Staff



Peggy Jo Archer

Project Coordinator
IA²



Emma Lynch

Project Assistant
IA²



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

IA² Initiatives



Mission & Vision

We help people and programs figure out how to competently and effectively access and serve Native American elders. We work to advance both knowledge and practice, and promote engagement at all levels – national, regional, and local. We acknowledge the history, rights, cultures, and value of indigenous people throughout their lifespans.

Responding to the needs of those we serve, we generate research, convene stakeholders to identify novel approaches to cross-cutting issues and work to bridge the gap between policy, research and practice.

IA² Initiatives



IA² Initiatives Home

Brain Health

Wandering

Caregiving

Vaccines

Ways to Participate



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

Native American Elder Justice Initiative (NAEJI) National Resource Center

History

Cooperative agreement with Administration for Community Living (ACL)



Established at National Indigenous Elder Justice Initiative, University of North Dakota



Awarded to IA² in 2022

NAEJI will promote locally tailored, culturally relevant activities to address the abuse, neglect, and exploitation of American Indian, Alaska Native, and Native Hawaiian (AI/AN/NH) elders and promote justice for the nation's Indigenous elders.

Goals of NAEJI

- Establish a robust and responsive national hub for elder abuse training, technical assistance, subject matter expertise access, and targeted resources for tribes and tribal staff
- Advance community engagement among organizations that serve tribes and tribal members and build local capacity by:
 - **Promoting innovative and best practices** for preventing elder abuse and exploitation and mitigating their impact, including through holistic assistance to victims
 - **Providing training and technical assistance** to strengthen adult protective services, including through the use of multidisciplinary teams and restorative justice
 - **Identifying evidence-informed and evidence-based** activities and resources that can be adopted for implementation with Native populations
 - **Identifying and disseminating model tribal codes** that support elder justice, similar to tribal codes protecting children, and providing technical assistance for implementation



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

My Advance Care Plan & Guide for Native Americans

This guide assists Indigenous people with planning for health issues, end-of-life decision-making, and sharing their wishes with loved ones.



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



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 of Rural Health and the University of North Dakota originally developed this document in partnership with the National Indigenous Elder Justice Initiative in 2022.



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

2. What Matters To Me

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 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.

I like to know...

only the basics

basic information
but not the details

all the details about
my condition and
my treatment



As doctors treat me, I would like...

my doctors to do
what they think best

shared decision
making with my
doctors

to have a say
in every decision



If I have an illness that will shorten my life, I prefer to...

know my doctor's
best estimate for
how long I have
to live

know what
stages to expect

not know how quickly
it is likely to progress



How involved do you want your loved ones to be?

I want them to do
exactly as I have
said, even if it
makes them
uncomfortable

I want a shared
discussion with my
loved ones

I want them to do
what brings them
peace, even if it goes
against what I have
said



When it comes to sharing information...

I don't want my
loved ones to know
anything about my
health

I want to decide what
information is shared

I am comfortable
with my loved ones
knowing everything
about my health



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:



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

I would like my treatment to be aimed at keeping me alive as long as possible. I wish to receive all treatments that the healthcare team think are appropriate to my situation.

The exceptions to this would be:

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

6. My Advance Directive

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

In the following circumstances:	I would like my care to focus on:	I would accept the following treatments:	I would wish to refuse or stop the following treatment:
Example: Severe stroke, unable to recognize anyone	Example: Allowing a natural death	Example: Comfort measures	Example: Artificial feeding

- 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:

My will and other important things can be found:

Document/item	Where it is	Notes
My will		

To save My Advance Care Plan on your own computer, go to File on the menu bar at the top of your screen, select Save As, enter a name and location where you want it saved, and click on Save.

SAVE

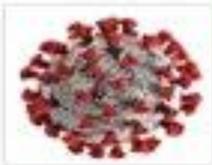
Restoring respect and dignity by honoring Indigenous Elders



National Indigenous Elder Justice Initiative

If this is an emergency, call 911. To report Elder abuse, neglect, or financial exploitation, view the [State/Tribal Hotlines](#) page for local numbers.

Most cases of Elder abuse are undetected, under reported, and unresolved resulting in injury, financial decimation, and even death. The National Indigenous Elder Justice Initiative (NIEJI) was created to address the lack of culturally appropriate information and community education materials on Elder abuse, neglect, and exploitation in Indian Country.



COVID-19 Resources

These [COVID-19 Tribal Elder Resources](#) will help to inform your communities on how to prevent the spread, protect your Elders and loved ones, and prevent falling for [scams](#).

Elder Abuse Warning Signs

- Learn more about the [types of abuse and the warning signs](#)



Native Elder Protection Team Toolkit

A [step-by-step guide](#) for developing a successful model for addressing Elder abuse in Indian Country. The [Toolkit](#) is designed to help you



Featured NIEJI Resource

[My Advance Care Plan & Guide for Native Americans](#)

This guide assists Indigenous people in planning for health issues, end-of-life decisions, and being able to share their wishes with loved ones.

Recent Podcasts

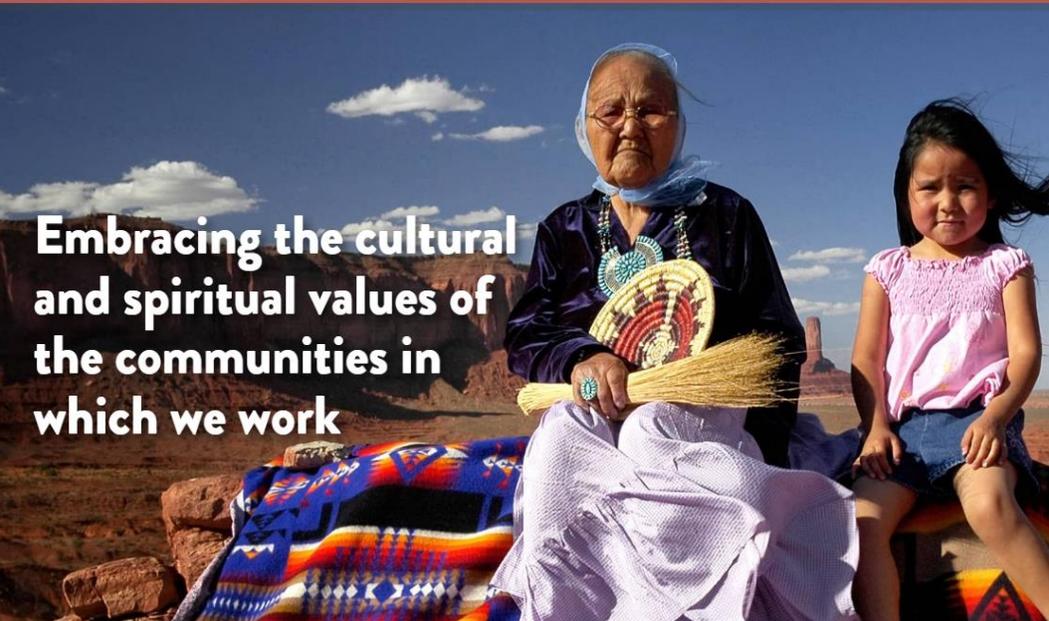
Listen to Dr. Jacque Gray talk about these issues in Indian Country:

- [Elder abuse](#)
- [Medication issues](#)



New Training Opportunities

- [Cultural Sensitivity Training](#)
- [Behavioral Health Online Interactive Module](#) (Also view [key information document](#))



**Embracing the cultural
and spiritual values of
the communities in
which we work**

Thank You for Attending



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Learn about cutting-edge efforts to improve aging care for American Indian & Native American communities



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International Association for
Indigenous Aging

admin@iasquared.org





Questions?

