The Many Facets of Advance Care Planning

March 23, 2022

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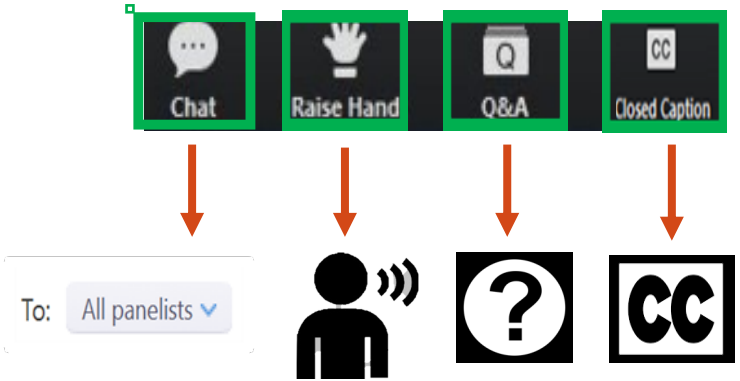

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Southcentral Foundation

Advance Care Planning

March 2022 LTSS Webinar

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2011 & 2017 Award Recipient

65,000 Voices

What Is Advance Care Planning?

"Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care [1]. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences [1]"

- https://www.uptodate.com/contents/advance-care-planning-and-advance-directives

Why Is ACP Important in Our Tribal Health Care System?

- Communication across system is often challenging
  - Geographically vast with multiple entry points for delivery of health care
  - Transient providers in rural sites
  - Variation in medical records/data storage systems
- Top 3 causes of death among Alaska Natives (ANs) are cancer, heart disease, and unintentional injury
  - 49.4% of all deaths are unexpected

Alaska Tribal Health System

An Overview

- Largest, most comprehensive tribal health organization in the United States
- More than 99% of Alaska's health programs are managed by tribes and Native organizations
- Serves 224 tribes; 180,000 AN or American Indian (AI) people throughout predominantly road-less land
- 1 tertiary hospital
    - Alaska's first Level II trauma center
    - 173 beds

anhb.org/tribal resources/alaska tribal health system/

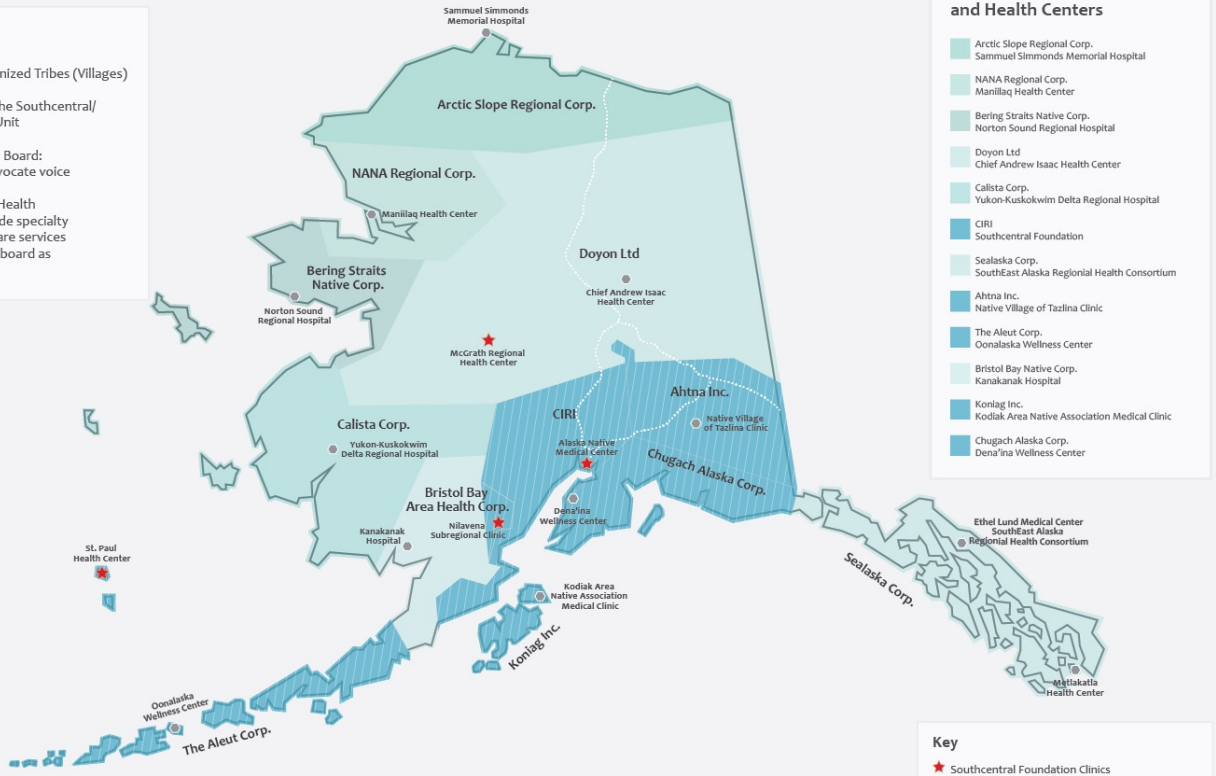
Alaska Is Larger Than Texas, California, and Montana Combined

591,000 Square Miles

Alaska Health System

Facts

- 229 Federally Recognized Tribes (Villages)
- Over 60 Villages in the Southcentral/ Anchorage Service Unit
- Alaska Native Health Board: Statewide health advocate voice
- Alaska Native Tribal Health Consortium: Statewide specialty and tertiary health care services Regionals seated on board as governance



Regional Native Corporations and Health Centers

- Arctic Slope Regional Corp. — Sammuel Simmonds Memorial Hospital
- NANA Regional Corp. — Maniilaq Health Center
- Bering Straits Native Corp. — Norton Sound Regional Hospital
- Doyon Ltd — Chief Andrew Isaac Health Center
- Calista Corp. — Yukon-Kuskokwim Delta Regional Hospital
- CIRI — Southcentral Foundation
- Sealaska Corp. — SouthEast Alaska Regional Health Consortium
- Ahtna Inc. — Native Village of Tazlina Clinic
- The Aleut Corp. — Oonalaska Wellness Center
- Bristol Bay Native Corp. — Kanakanak Hospital
- Koniag Inc. — Kodiak Area Native Association Medical Clinic
- Chugach Alaska Corp. — Dena'ina Wellness Center

Key

- Southcentral Foundation Clinics
- Southcentral Foundation/Anchorage Service Unit
- Regional Health Hub

McGrath Regional
Health Center
McGrath

Indian Creek Health Clinic
Tyonek

C'eyiits Hwnax Life House
Community Health Center
Sutton

St. Paul Community
Health Center
St. Paul Island

SCF

Port Alsworth Health Center
Port Alsworth

Nilavena Subregional
Health Center
Iliamna

SCF Community Health Centers

Where Do We Start?

- Upstream
- Proactive
- Enhance communication between customer-owners, families, and health care employees
- Identify customer-owner goals, wishes, and preferences
  - Anticipate needs
  - Provide meaningful interventions
  - Keep customer-owners home in their communities

Benefits of Rural Health Care

- Reduced stress
  - Limited travel and care coordination
- Stronger sense of community and connection
  - Informal and organic
- Public journey of survivorship
  - Gain strength and inspiration
- Comfort and normalcy at death

McNulty, J.A., & Nail, L. (2015). Cancer survivorship in rural and urban adults: A descriptive and mixed methods study. *The Journal of Rural Health, 31*(3), 282–291. https://doi: 10.1111/jrh.12106

How Does ACP Help Our Customer-Owners?

- Honors the wishes of AN and AI people
- Clarifies goals and preferences
- Improves communication
- Satisfies Meaningful Use requirements
- Promotes quality of life

Other benefit: Following the wishes of AN and AI people often leads to the conservation of scarce resources

Advance Care Planning Pilot

Goal: To integrate advance care planning discussions for customer-owners age 40 and older as part of routine screening and health promotion behaviors

Interventions:

- Global needs assessment
- Culturally adapted materials and tools
- Clinical workflow
- Electronic health record (EHR) enhancement
- Health care provider education
- Quality assurance – Plan Do Study Act
  - Alaska Native Medical Center (oncology, cardiology inpatient medical/surgical, and ICU)
  - Southcentral Foundation (1 West Primary Care Clinic)

Customer-Owner Insights

- Fewer words/simplify the content
- Make the documents easily translatable to AN languages
- Replace jargon with plain language
- Omit non-essential details
- Provide more information on how advance directives (ADs) can be relevant for different diseases
- Offer more educational resources
- Involve families in decision making
- Do not take away hope

Provider Insights

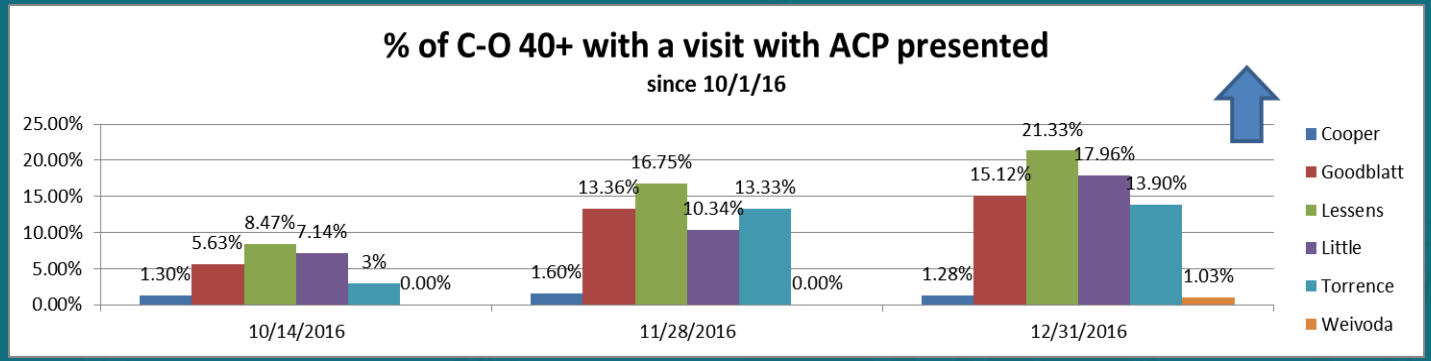
- Need ADs that provide clear guidance for medical interventions
- Introduce ADs early, ideally in the outpatient setting
- Implement ACP conversations that are realistic
- Improve ongoing communication re: goals of care throughout health care teams
- Engage patients in conversations about medical goals, values, and preferences
- Develop simple ACP tools and resources that help with ACP conversations

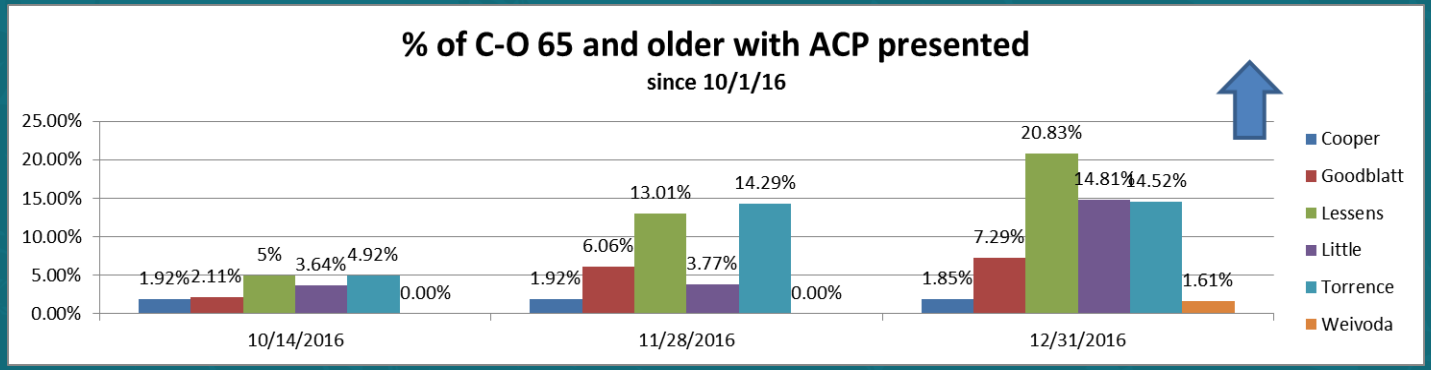
Advance Care Planning Pilot Data

- **Process and teamwork**
  - Time dictates initiation of conversation
  - Reliance on support staff (behavioral health consultants) to have longer conversation
- **Tools and technology**
  - Feedback re: materials was overwhelmingly positive
  - Process integration was difficult for busy clinics
  - Use of electronic tracking system needs work
- **Conversations and patients**
  - The staff felt more positive and confident in their ability to initiate conversations
  - Patients demonstrated good understanding of the materials
  - Majority need help in filling out documents

PCP teams increased proficiency over time.

Goal for the Meaningful Use metric for ADs is 50% of customer-owners (C-O) age 65 and older should have an AD documented in their EHR.



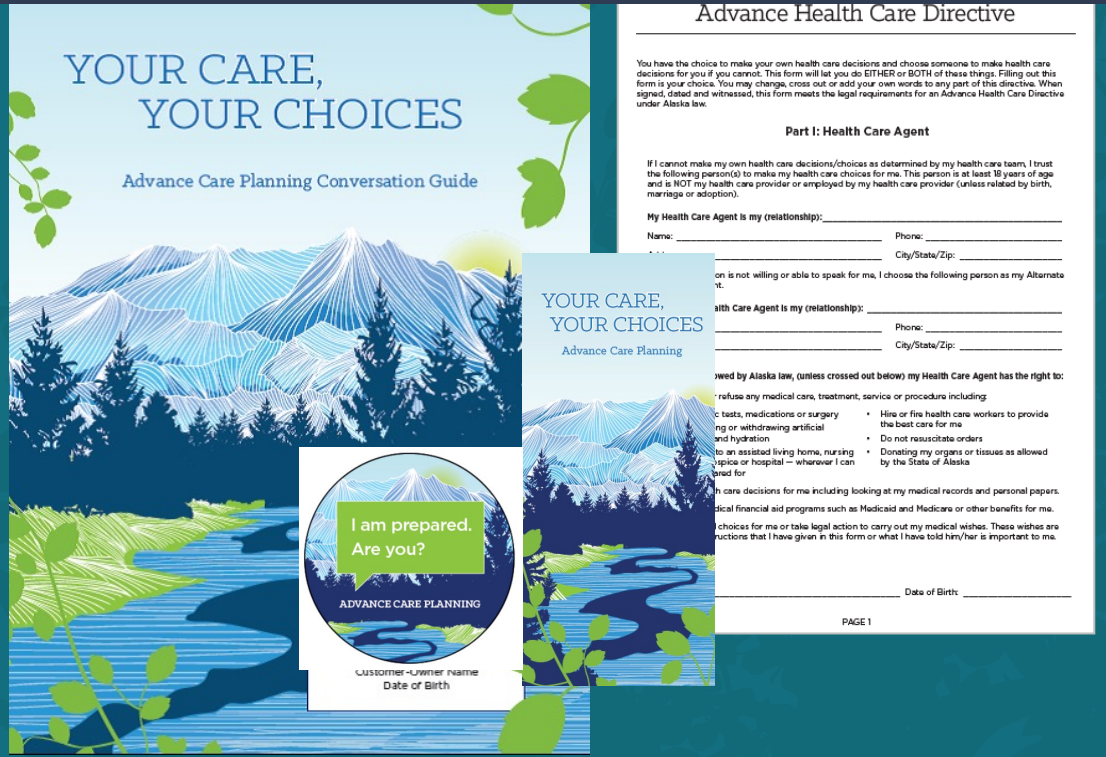


Advance Care Planning Materials: Development

"Your Care, Your Choices"

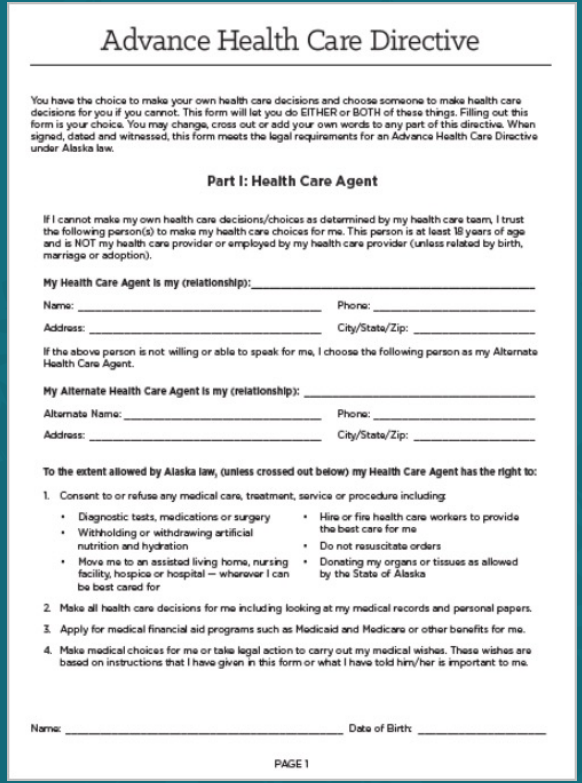
- Advance Health Care Directive
- ACP Conversation Guide
- ACP Brochure
- ACP Awareness Button

Available on our ANTHC palliative care website!
www.anthc.org/palliative-care/resources/



Advance Health Care Directive

- Medical content mirrors the Alaska Physician Orders for Life-Sustaining Treatment
- Simple language
  - Easily translatable for customer-owners and providers
- Integrates personal preferences
- Flesch-Kincaid Reading Level: 6



Advance Health Care Directive

You have the choice to make your own health care decisions and choose someone to make health care decisions for you if you cannot. This form will let you do EITHER or BOTH of these things. Filling out this form is your choice. You may change, cross out or add your own words to any part of this directive. When signed, dated and witnessed, this form meets the legal requirements for an Advance Health Care Directive under Alaska law.

Part I: Health Care Agent

If I cannot make my own health care decisions/choices as determined by my health care team, I trust the following person(s) to make my health care choices for me. This person is at least 18 years of age and is NOT my health care provider or employed by my health care provider (unless related by birth, marriage or adoption).

My Health Care Agent is my (relationship): _____

Name: _____ Phone: _____

Address: _____ City/State/Zip: _____

If the above person is not willing or able to speak for me, I choose the following person as my Alternate Health Care Agent.

My Alternate Health Care Agent is my (relationship): _____

Alternate Name: _____ Phone: _____

Address: _____ City/State/Zip: _____

To the extent allowed by Alaska law, (unless crossed out below) my Health Care Agent has the right to:

1. Consent to or refuse any medical care, treatment, service or procedure including:
   - Diagnostic tests, medications or surgery
   - Withholding or withdrawing artificial nutrition and hydration
   - Move me to an assisted living home, nursing facility, hospice or hospital — wherever I can be best cared for
   - Hire or fire health care workers to provide the best care for me
   - Do not resuscitate orders
   - Donating my organs or tissues as allowed by the State of Alaska
2. Make all health care decisions for me including looking at my medical records and personal papers.
3. Apply for medical financial aid programs such as Medicaid and Medicare or other benefits for me.
4. Make medical choices for me or take legal action to carry out my medical wishes. These wishes are based on instructions that I have given in this form or what I have told him/her is important to me.

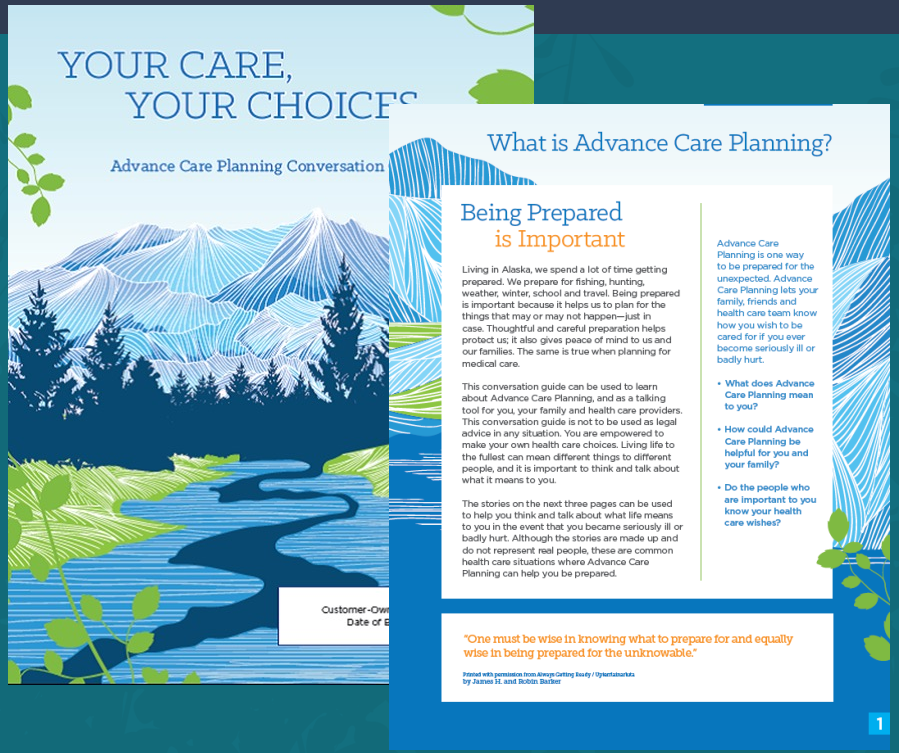
Name: _____ Date of Birth: _____

PAGE 1

Advance Care Planning Conversation Guide

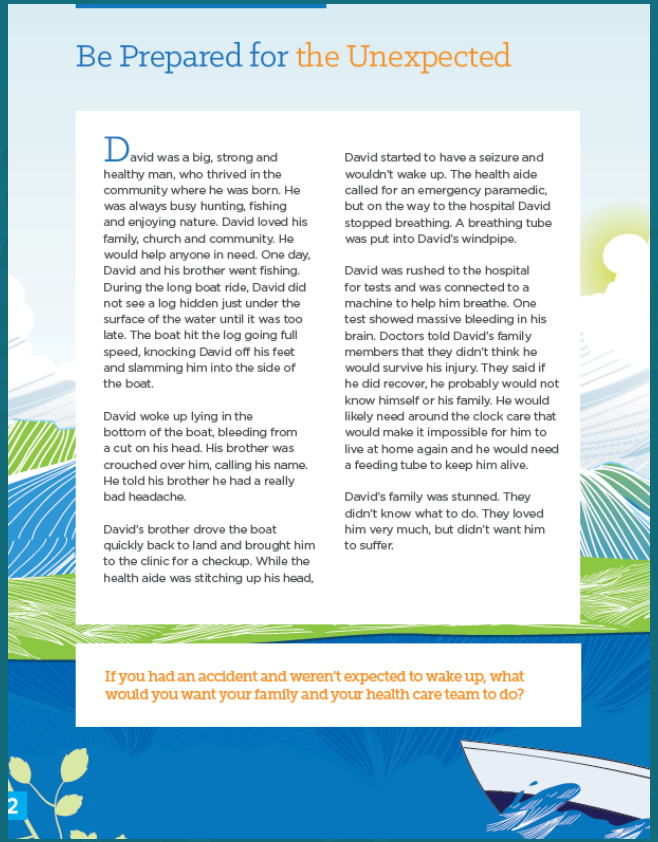
Theme: “Be Prepared”

- Culturally inclusive
- Intentional design
  - Customer owner education
  - Facilitators guide
- Easily translatable



Incorporating Storytelling

- Integration of AN culture
- Three real-life scenarios addressing decision points
  - Unexpected
    - Young, healthy
  - Journey
    - New diagnosis, progression of disease
  - Transition
    - Elders, multiple medical problems, approaching the end of life



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?

2

Facilitator's Guide

- Suggested scripting
  - Brief overview of information
  - Color-coded
- Open-ended questions
  - Conversational tone/conversation starter
  - Customer-centered discussion
  - Encourages interaction
- Content linked by page number to Advance Health Care Directive

What is Life Support?

Life support treatments include any medical test, blood product, surgery, procedures, machine and/or medicine needed to help prolong life. Life support is 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.

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're 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 poisons.

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?**

Make choices about life support treatments on page 4 of the Advance Health Care Directive

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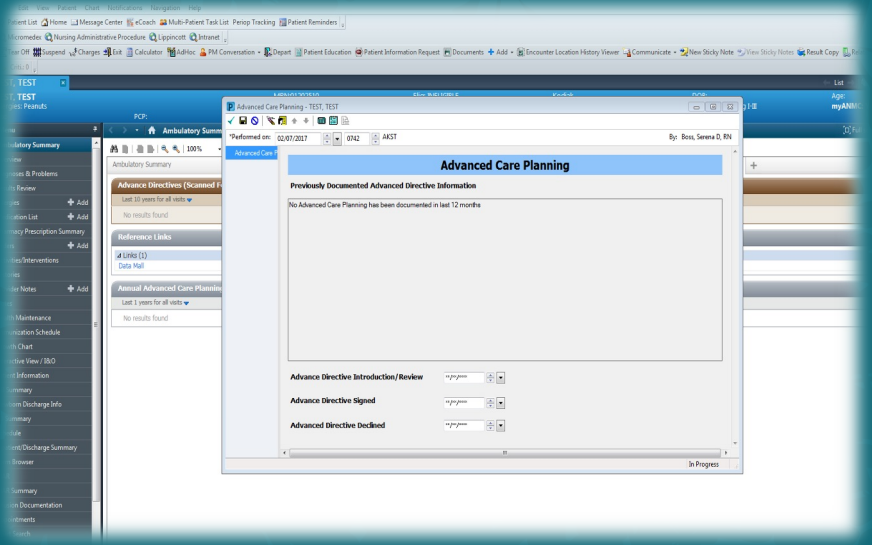
Wellness Map

- Complements existing ACP materials
- Culturally relatable
- Integrates symbolism
- Can be tailored to each individual
- Useful for navigating most medical complexities

Integrating Advance Directives in EHR

- Develop Cerner workflow
- Implement AD tab
  - Hyperlink to actual document
- Identify ADs via banner bar
- Utilize QuickLook to flag patients needing ADs in outpatient settings
- Pilot system change within oncology, specialty clinics, inpatient settings, and Southcentral Foundation primary care



Future Direction

- Continue to strengthen and optimize existing workflows
  - Public relations campaign
  - Expanding outpatient ACP conversations and use of ACP tools and resources
  - Electronic referral for ACP group visits
- Share ACP tools and resources with Indian Health Service and interested organizations
- Integration and normalization within Aging Well Initiative
- Conducting research on ACP tools and resources

Questions?

Contact Southcentral Foundation's Learning Institute for more information

SCFNukaEvent@scf.cc

(907) 729-NUKA

www.SCFNuka.com

Thank You!

Qaĝaasakung
Aleut

Quyanaa
Alutiiq

Quyanaq
Inupiaq

Awa'ahdah
Eyak

Mahsi'
Gwich'in Athabascan

Igamsiqanaghalek
Siberian Yupik

Háw'aa
Haida

Quyana
Yup'ik

T'oyaxsm
Tsimshian

Gunalchéesh
Tlingit

Tsin'aen
Ahtna Athabascan

Chin'an
Dena'ina Athabascan

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