The Many Facets of Advance Care Planning

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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].”

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 advocate voice
- Alaska Native Tribal Health Consortium: Statewide specialty and tertiary health care services Regionalis seated on board as governance

Regional Native Corporations and Health Centers
- Arctic Slope Regional Corp.
- Sealaska Heritage Institute
- NANA Regional Corp.
- Maniilaq Health Center
- Bering Straits Native Corp.
- Norton Sound Health Corporation
- Doyon Ltd.
- Chief Andrew Isaac Health Center
- Calista Corp.
- Yukon-Kuskokwim Delta Regional Hospital
- CRI
- Southcentral Foundation
- Sóolkáa Corp.
- SouthEast Alaska Regional Health Consortium
- Aféna Inc.
- Native Village of Takuak Clinic
- The Next Corp.
- Onmusha Wellness Center
- Bristol Bay Native Corp.
- Kake Health
- Koniag Inc.
- Kuskokwim Region Indian Association Medical Clinic
- Ciichgich Akusak Corp.
- Dove Yee Wellness Center

Key
- Southcentral Foundation Clinics
- Southcentral Foundation/Anchorage Service Unit
- Regional Health Hub
Where Do We Start?

- Upstream
- Proactive
- Enhance communication between customer-owners, families, and healthcare 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

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
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
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 products, 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 doctor 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 “breathe 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 persistent tube in your nose 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 body. 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 bloodstream 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 clotting factors. Blood products are often donated by other people and are put directly into the blood stream through an IV.

Life support 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.
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

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Thank You!

Qaγaasakung  Aleut
Quyanaa   Alutiiq
Quyanaq   Inupiaq
Awa'ahdah  Eyak

Mahsi'  Gwich’in Athabascan
Igamsiqanaghalek  Siberian Yupik
Háw'aa  Haida

Quyana  Yup’ik
T’oyaxsm  Tsimshian

Gunalchééesh  Tlingit

Tsin'aen  Ahtna Athabascan
Chin’an  Dena’ina Athabascan