Palliative Care and Advance Care Planning in AK

Sean Timpane MD

ANTHC Palliative Care

"Before I give you your results, I'm going to put on some very sad music."

https://twitter.com/RossAlbertMD/status/616746695540502528/photo/1

Objectives

Parse the palliative care word salad

Explore primary palliative care tools and resources

Explore how COVID might change and even augment the way we help our patients prepare for serious illness

Show a simulated demonstration of a successful serious illness conversation

There are so **MANY** Palliative Words!

Palliative = to alleviate, lessen, mitigate

Palliative Care

Primary/Specialty Palliative Care

Palliative Treatment or Surgery

Hospice

Comfort Care

A patient is NOT palliative in the U.S.

"About your cat, Mr. Schrödinger—I have good news and bad news."

Palliative Care is Patient and Family-Centered Care

Palliative care is care focused on maximizing quality of life during any and all stages of a serious illness

Provides relief from symptoms and stress of illness

Improves quality of life for both the patient and the family

Appropriate at any age and at any stage of a serious illness – and it can be provided along with curative and life-prolonging treatment in any care setting

Palliative care is based on patient and family needs, not prognosis

https://www.capc.org/about/press-media/press-releases/2018-4-18/center-to-advance-palliative-care-statement-clarifying-the-definition-of-palliative-care/

"There's no easy way I can tell you this, so I'm sending you to someone who can."

https://fineartamerica.com/featured/there-is-no-easy-way-i-can-tell-you-this-peter-c-vey.html

The Palliative Care Ideal

Interdisciplinary

Extended patient or family-led conversational visits

Continuity across care settings

Early introduction and prolonged involvement

Palliative Care is NOT

Palliative Care is sometimes

"Don't freak out—it's just a save-the-date."

There are 5’ish Elements of a Comprehensive Palliative Care Visit

Illness Understanding – Assessment and Update

Goals of Care

Advance Care Planning +/- Code Status

Symptom Evaluation

Quality of Life and Social Support

*Response to emotion and distress throughout

Communication Tools

Ask, Tell, Ask

Tell Me More

NURSE – Naming, Understanding, Respecting, Supporting and Exploring

Most Palliative Care is **NOT** provided by a Specialty Team and that is **GOOD**

Anyone who takes care of patients with serious illness is doing palliative care

Primary relationships with patients are irreplaceable

Uncomfortable/difficult aspects of Palliative Care

- Having the time!
- Discussing difficult news
- Responding to BIG emotions

Hospice and Comfort Care are very specific forms of care for patients nearing EOL

Hospice is a medical benefit with limited access in AK

Comfort Care is symptom-focused EOL care

- Can be surprisingly aggressive or even invasive
- Care is tailored to patient needs and desires

Palliative Care in the Tribal Health System

ANTHC Palliative Care Specialty Team
- Inpatient @ ANMC: MD + CNS
- Outpatient in Oncology Clinic: LCSW
- Regional Support via phone, VTC, AFHCAN
- Phone: 729-1112 M-F or Tiger Text directly to providers

Palliative Care ECHO

Southcentral Foundation

Hospice: Anchorage, Fairbanks, Juneau

Additional Resource for Staff

Free CAPC Memberships with ANTHC email address

- Clinical resources
- Educational modules
- www.capc.org

5 Courses

5 Completed

Available to non-members

Nausea and Vomiting

Identifying and managing nausea and vomiting for patients living with serious illness and their car...

VIEW

Completed on Sept. 5, 2017

Available to non-members

Dyspnea

Reducing physical and emotional suffering from dyspnea for patients with serious illness.

VIEW

Completed on Sept. 5, 2017

Available to non-members

Constipation

Assessing and managing constipation in people with serious illness.

VIEW

Completed on Sept. 6, 2017

Available to non-members

Anxiety

Prevalence, screening recommendations, and evidence-based strategies to treat anxiety in patients w...

VIEW

Completed on Sept. 6, 2017

Available to non-members

Depression

Prevalence, screening recommendations, and evidence-based strategies to treat depression in patient...

VIEW

Completed on Sept. 5, 2017

Advance Care Planning

Process to understand a patient's personal values, life goals, and preferences regarding future medical care

Will hopefully lead patients to receive medical care that is consistent with their values, goals, and preferences

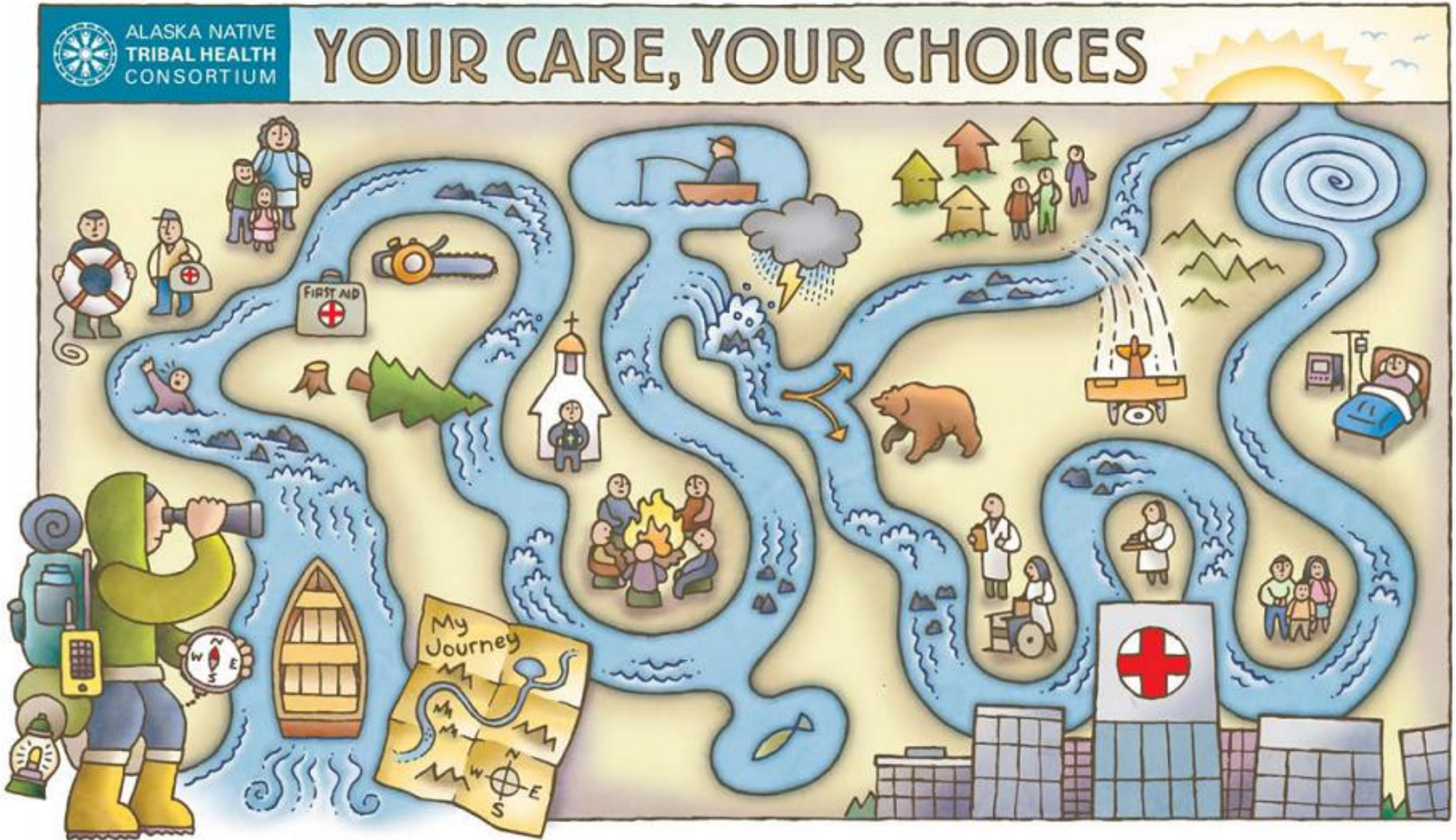
Should be proactive, appropriately timed, and integrated into routine care.

Should be revisited every time a person's medical condition changes

Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage 2017; 53:821.

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

YOUR CARE, YOUR CHOICES



Advance Care Planning is a Collaborative Process

Understand a patient's goals and values

Identify and ideally include a health care agent and/or trusted medical decision maker

As the medical expert, provide recommendations

Be prepared to respond to emotion – DON'T FIX

Complete or update an Advance Directive – copy/scan/share

Advance Directives and Comfort Ones

Advance Directives aka Living Wills

- Examples include 5 wishes and Providence Short Form
- Part 1: Choosing a healthcare agent aka proxy or healthcare power of attorney
- Part 2: Medical wishes
- Link to ANTHC form: - https://anthc.org/wp-content/uploads/2017/02/Advance-Directive-Form-_LOW-RES.pdf

Comfort One Program

- AK specific, in lieu of POLST or MOLST in other states
- Limited to terminally ill patients who wish to avoid resuscitation (DNR
- Shared with emergency services and law enforcement for expected home deaths

The COVID Pandemic Should Lead to MORE Advance Care Planning

Seriously ill or complex patients already uncertain

Less frequent or remote contact with medical providers

COVID course can be rapid, severe

Preparation can be empowering

Goal-directed resource use

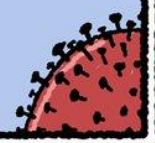
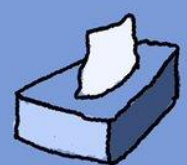
An Embarrassment of Free Resources

CAPC COVID-19 Resources
https://www.capc.org/toolkits/covid-19-response-resources/

Serious Illness Care Program COVID-19 Response Toolkit (includes videos)
https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/

Vital Talk COVID-19 Communication Script
https://www.vitaltalk.org/guides/covid-19-communication-skills/

C.A.L.M.E.R. – COVID as starting place for advance planning

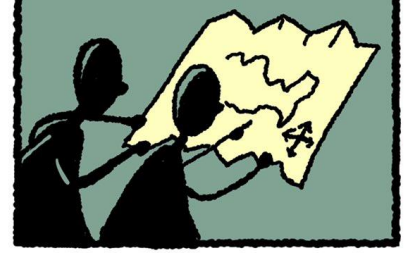
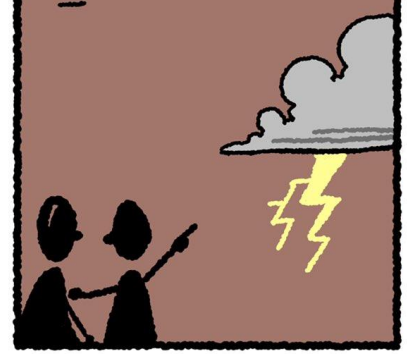
C Check in 	"How are you doing with all of this? Where do you find comfort/support?"
A Ask about COVID 	"What have you been thinking about COVID and your situation?"
L Lay out issues 	"Is there anything you would want us to know if you got COVID/ if your COVID gets bad?"
M Motivate to choose a proxy and talk 	"Who would speak for you if things got bad?" "What matters most to you?" "Based on what you've said, I recommend ____. What do you think?"
E Expect emotion 	"This can be really hard to talk about..." Allow silence. @NathanAGray
R Record the discussion 	Any documentation can be very helpful to colleagues and your patient. "I'll record what you've said for both of us. It's very meaningful. Thank you."

Nathan A. Gray, MD

Text adapted from VitalTalk

www.vitaltalk.org/guides/covid-19-communication-skills/

COVID – Discussing CPR

Context 	<u>What is the setting of this conversation?</u> -Is it a good time/place to talk? -What has someone heard about serious illness from COVID? What have they been told about their own condition? -What matters most to them? "Would it be alright for us to talk about what to do if things get worse?"
Concern 	<u>Why do we need to talk about CPR now?</u> -Is their condition getting worse? -Does their medical history place them at high risk of dying from COVID? "I'm worried that if this gets worse, you could reach the point where you are dying." If appropriate for condition: "In situations like this, CPR is not likely to help."
Counsel @NathanAGray 	<u>Based on their medical condition and values, what do you recommend?</u> "Based on your situation and what you've told me, I do/don't recommend attempting CPR." When recommending against CPR: "If things get so bad that you're dying, I recommend we do everything possible for your comfort and not attempt CPR. What do you think?"

Nathan A. Gray, M.D.

www.inkvessel.com

Serious Illness Conversation Guide

COVID-19 Conversation Guide for Outpatient Care

SET UP

This is a difficult and scary time with the coronavirus. I'm hoping we can talk about **what is important to you**, so that we can provide you with the best care possible. **Is that okay?**

ASSESS

What do you **understand** about how the coronavirus could affect your health?

What are you currently doing to **protect yourself** from getting the virus?

May I share with you **my understanding** of how the coronavirus could affect your health?

SHARE

Most people who get the coronavirus get better on their own. However, people who are older or have other health problems **like yours** can get very sick and may not survive. The treatments that we use to try to help people live, like breathing machines, may not work. If they do work, recovery from the illness is uncertain. ***[Pause, respond to emotion].***

We really hope that you don't get the virus, but it is important **to prepare** in case you do.

Given your [medical condition]/age, I'd like to think together about what would be important to you if you became very sick and couldn't speak for yourself.

Serious Illness Conversation Guide

EXPLORE

What would be **most important** for your healthcare providers or loved ones to know if you became very sick and couldn't speak for yourself?

With all that's going on, what are you most **worried** about?

What **abilities** are so important to you that you can't imagine living without them?

If we think they may not help or may cause suffering, some people make decisions to avoid treatments like breathing machines or CPR if they get very sick. If that happened to you, have you thought about **medical treatments** that you may or may not want?

How much do your **loved ones** know about your priorities and wishes?

CLOSE

This can be hard to talk about. At the same time, this conversation can help us ensure that **what matters most to you** guides your care if you get sick.

I've heard you say ____. I think it's important to **share this information with your loved ones** so they can speak for you if you can't. I recommend that we complete a healthcare proxy so we know who you trust to make decisions if you can't.

[If additional recommendations] I also recommend ____.

This is an uncertain time for all of us. **We will do everything we can** to help you and your family through this.

SI-CG-COVID 2020-04-03

ARIADNE LABS

An Example Telehealth Encounter

https://youtu.be/Va6lTUcm85M

Palliative Care and ACP Summary

We all can and should integrate palliative care principles into our work

COVID 19 gives us all a useful context to learn more about our patients

Learning about goals and values before a crisis empowers patients AND providers

Short of crisis standards, care will and should remain goal-directed

It’s ok to use scripts and guides no matter how experienced

Be present and don’t be afraid to respond to emotion

Efficiency is gained in improved understanding and communication over time

Questions?

Sean Timpane – sftimpane@anthc.org