Supporting Palliative Care Outreach in Rural Populations

December 8, 2021

Pat Justis, MA; Salom Teshale, PhD

HCBS Conference

NASHP
NATIONAL ACADEMY
FOR STATE HEALTH POLICY

The John A. Hartford
Foundation

Introduction to Palliative Care

- Speaker: Salom Teshale, Policy Associate, National Academy for State Health Policy

Background

- National Academy for State Health Policy (NASHP)
  - Non-partisan academy of and for state officials
  - 30+ year history in helping state policy leaders lead and implement innovative policies

Overview

- What is palliative care?
- Why is it important for states?
- Where are there gaps in knowledge about palliative care?

Serious illness is “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains the caregiver.”

Kelley and Bollens-Lund, 2018

What is palliative care?

- National Consensus Project: “a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness”
- Specialized services for people with complex or serious illness that provide symptom relief, stress relief, and support person-centered goals
  - Includes an interdisciplinary care team
  - Can be delivered across settings, including hospital settings and home-based settings
  - Can be provided through the continuum of care / in addition to curative care

Why is it important for states?

- Evidence shows that palliative care can support improved patient quality of life and is related to lowering avoidable costs
- Morrison et al., 2011: Palliative care related to savings for Medicaid enrollees with serious illness
- States can support awareness of and sharing information about palliative care

Where are there gaps in knowledge about palliative care?

- Underserved populations:
  - CAPC: 94% of large hospitals have palliative care teams; 60% of public hospitals have palliative care teams
  - Many palliative care programs are within hospitals, so communities with fewer hospitals may not have equivalent access if home-based programs are not also present
  - Access to palliative care outside hospice contexts
  - Access & uptake

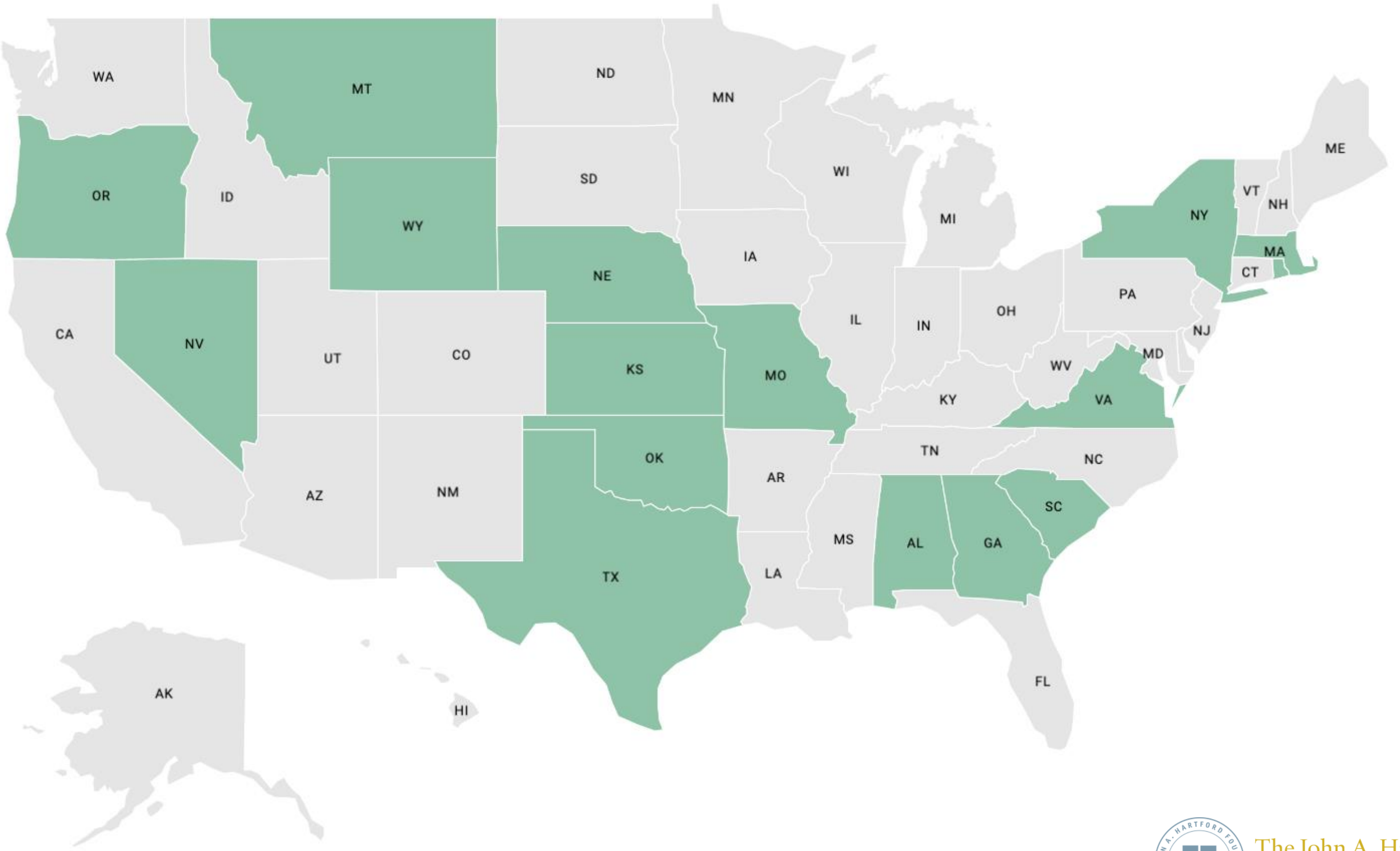
State strategies to raise awareness about palliative care

- Policy levers include:
  - **Support outreach to communities**

State strategies to raise awareness about palliative care

- **Support outreach to communities**
  - Palliative care task forces
  - Public education information campaigns and content

States with Palliative Care Task Forces



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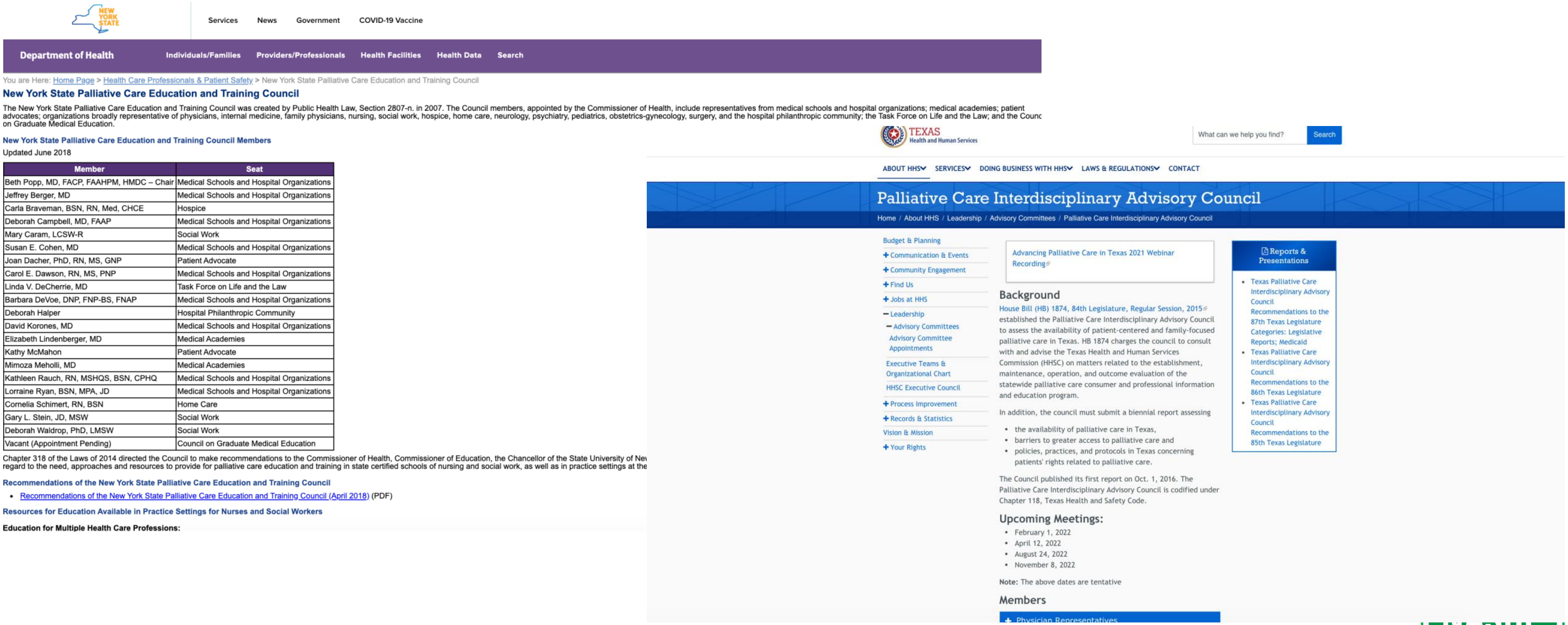
States with Palliative Care Task Forces



Services News Government COVID-19 Vaccine

Department of Health Individuals/Families Providers/Professionals Health Facilities Health Data Search

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New York State Palliative Care Education and Training Council

The New York State Palliative Care Education and Training Council was created by Public Health Law, Section 2807-n. in 2007. The Council members, appointed by the Commissioner of Health, include representatives from medical schools and hospital organizations; medical academies; patient advocates; organizations broadly representative of physicians, internal medicine, family physicians, nursing, social work, hospice, home care, neurology, psychiatry, pediatrics, obstetrics-gynecology, surgery, and the hospital philanthropic community; the Task Force on Life and the Law; and the Counc on Graduate Medical Education.

New York State Palliative Care Education and Training Council Members

Updated June 2018

Member	Seat
Beth Popp, MD, FACP, FAAHPM, HMDC – Chair	Medical Schools and Hospital Organizations
Jeffrey Berger, MD	Medical Schools and Hospital Organizations
Carla Braveman, BSN, RN, Med, CHCE	Hospice
Deborah Campbell, MD, FAAP	Medical Schools and Hospital Organizations
Mary Caram, LCSW-R	Social Work
Susan E. Cohen, MD	Medical Schools and Hospital Organizations
Joan Dacher, PhD, RN, MS, GNP	Patient Advocate
Carol E. Dawson, RN, MS, PNP	Medical Schools and Hospital Organizations
Linda V. DeCherrie, MD	Task Force on Life and the Law
Barbara DeVoe, DNP, FNP-BS, FNAP	Medical Schools and Hospital Organizations
Deborah Halper	Hospital Philanthropic Community
David Korones, MD	Medical Schools and Hospital Organizations
Elizabeth Lindenberger, MD	Medical Academies
Kathy McMahon	Patient Advocate
Mimoza Meholli, MD	Medical Academies
Kathleen Rauch, RN, MSHQS, BSN, CPHQ	Medical Schools and Hospital Organizations
Lorraine Ryan, BSN, MPA, JD	Medical Schools and Hospital Organizations
Cornelia Schimert, RN, BSN	Home Care
Gary L. Stein, JD, MSW	Social Work
Deborah Waldrop, PhD, LMSW	Social Work
Vacant (Appointment Pending)	Council on Graduate Medical Education

Chapter 318 of the Laws of 2014 directed the Council to make recommendations to the Commissioner of Health, Commissioner of Education, the Chancellor of the State University of Nev regard to the need, approaches and resources to provide for palliative care education and training in state certified schools of nursing and social work, as well as in practice settings at the

Recommendations of the New York State Palliative Care Education and Training Council

- Recommendations of the New York State Palliative Care Education and Training Council (April 2018) (PDF)

Resources for Education Available in Practice Settings for Nurses and Social Workers

Education for Multiple Health Care Professions:

Palliative Care Interdisciplinary Advisory Council

Home / About HHS / Leadership / Advisory Committees / Palliative Care Interdisciplinary Advisory Council

Advancing Palliative Care in Texas 2021 Webinar Recording

Background

House Bill (HB) 1874, 84th Legislature, Regular Session, 2015 established the Palliative Care Interdisciplinary Advisory Council to assess the availability of patient-centered and family-focused palliative care in Texas. HB 1874 charges the council to consult with and advise the Texas Health and Human Services Commission (HHSC) on matters related to the establishment, maintenance, operation, and outcome evaluation of the statewide palliative care consumer and professional information and education program.

In addition, the council must submit a biennial report assessing

- the availability of palliative care in Texas,
- barriers to greater access to palliative care and
- policies, practices, and protocols in Texas concerning patients' rights related to palliative care.

The Council published its first report on Oct. 1, 2016. The Palliative Care Interdisciplinary Advisory Council is codified under Chapter 118, Texas Health and Safety Code.

Upcoming Meetings:

- February 1, 2022
- April 12, 2022
- August 24, 2022
- November 8, 2022

Note: The above dates are tentative

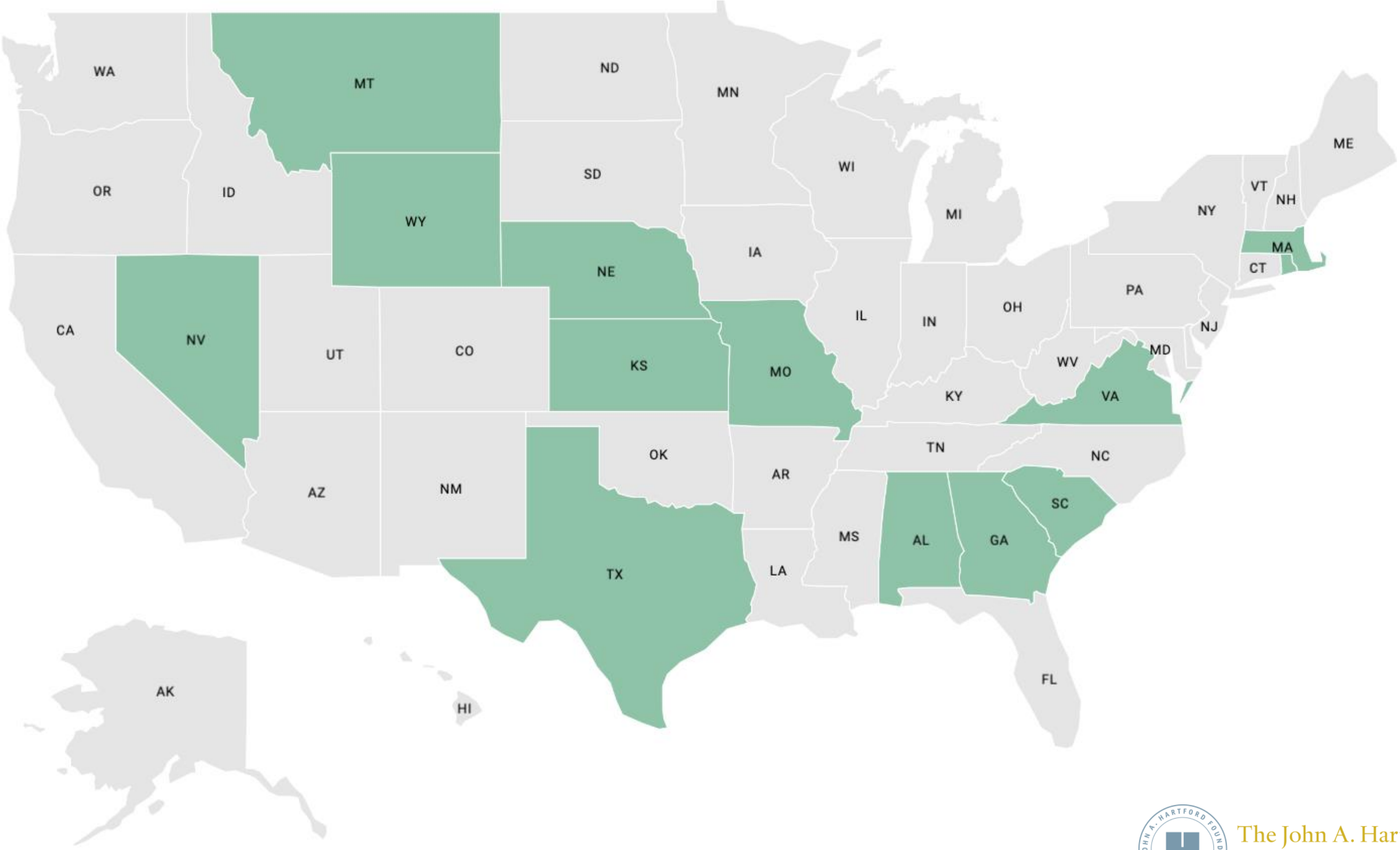
Members

+ Physician Representatives

Reports & Presentations

- Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 87th Texas Legislature Categories: Legislative Reports; Medicaid
- Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 86th Texas Legislature
- Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 85th Texas Legislature

States with Palliative Care Public Education Webpages



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States with Palliative Care Public Education Webpages

PALLIATIVE CARE

Palliative care is an approach to care that focuses on improving the quality of life for patients and their caregivers coping with a life-threatening illness or injury. Palliative care centers on preventing, diagnosing, and treating physical, emotional, social and spiritual sources of distress. It is important to know that although hospice is a form of palliative care, palliative care is not hospice. While hospice is designed to meet the needs of patients at the end-of-life, palliative care may be given at any time during an illness or injury, from the point of diagnosis onwards.

What is Palliative Care?

Palliative Care:

- Uses the expertise of a multidisciplinary team (physicians, nurses, social workers, chaplains) to comprehensively address the needs of a patient
- Provides support to help patients live as actively as possible
- Incorporates emotional and spiritual support into patient care
- Provides a support system to help the family cope during the patient's illness or injury
- Can be incorporated early in treatment, as well as during the end of life
- Is not prognosis or diagnosis dependent
- Is attuned to providing care that is aligned with the patient's values and goals

States with Palliative Care Public Education Webpages

Kansas Department of Health and Environment

Laura Kelly, Governor
Lee A. Norman, M.D., Secretary

Palliative Care

If you or your loved one has a serious, potentially life-limiting condition it is important to seek out and receive palliative pronounced (pal-lee-uh-tiv) care.

Explore our other resources and pages to learn more about palliative care in Kansas.

Program Overview

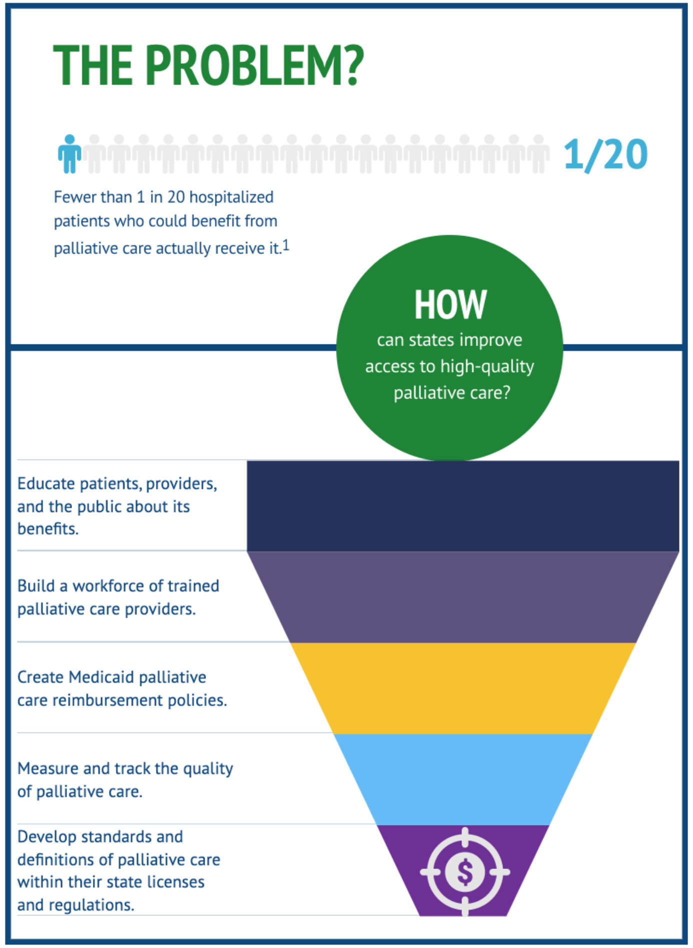
Brochure

Infographic

Kansas.gov | Privacy Notice | About KDHE | Contact Us | Directions | Open Records | WebMail | Webmaster

© 1996-2021 Kansas Department of Health and Environment
Curtis State Office Building, 1000 SW Jackson, Topeka, Kansas 66612

Reaching state policymakers



THE PROBLEM?

1/20

Fewer than 1 in 20 hospitalized patients who could benefit from palliative care actually receive it.[1]

HOW can states improve access to high-quality palliative care?

- Educate patients, providers, and the public about its benefits.
- Build a workforce of trained palliative care providers.
- Create Medicaid palliative care reimbursement policies.
- Measure and track the quality of palliative care.
- Develop standards and definitions of palliative care within their state licenses and regulations.

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NASHP's Palliative Care Work

- How States Can Frame the Message and Gather Support
- Building Infrastructure and Promoting Quality
- Sustainability and Value: State Reimbursement Strategies

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Thank You

Disclosure: I have no commercial relationships to disclose.

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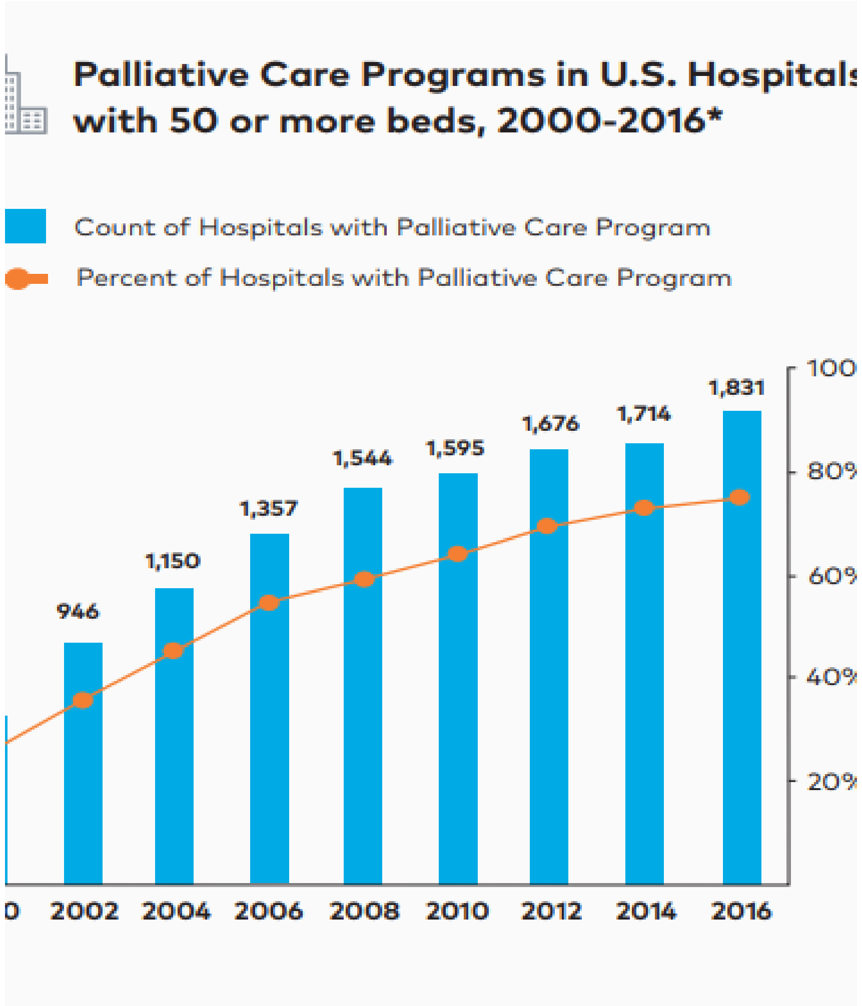
DECREASING RURAL INEQUITIES IN ACCESS TO PALLIATIVE CARE

Pat Justis, MA, Executive Director,
Washington State Office of Rural Health

Objectives

- Describe the rural inequities in access to palliative care (PC) services
- Describe a community engagement driven model for rural and the advantages of a Learning Action Network (LAN)
- Describe how rural PC services differ from urban and suburban
- Discuss the WA model
- Offer ideas on how other states can begin to develop rural PC

Most rural hospitals in the west have 25 beds or less…



“Over the past 16 years, the percentage of hospitals (50 or more beds) with a palliative care program has tripled.”

“growth-of-palliative-care-in-us-hospitals-2018-snapshot-2000-2016%20(1).pdf”
Center for the Advancement of Palliative Care (CAPC) Accessed 10/22/2021

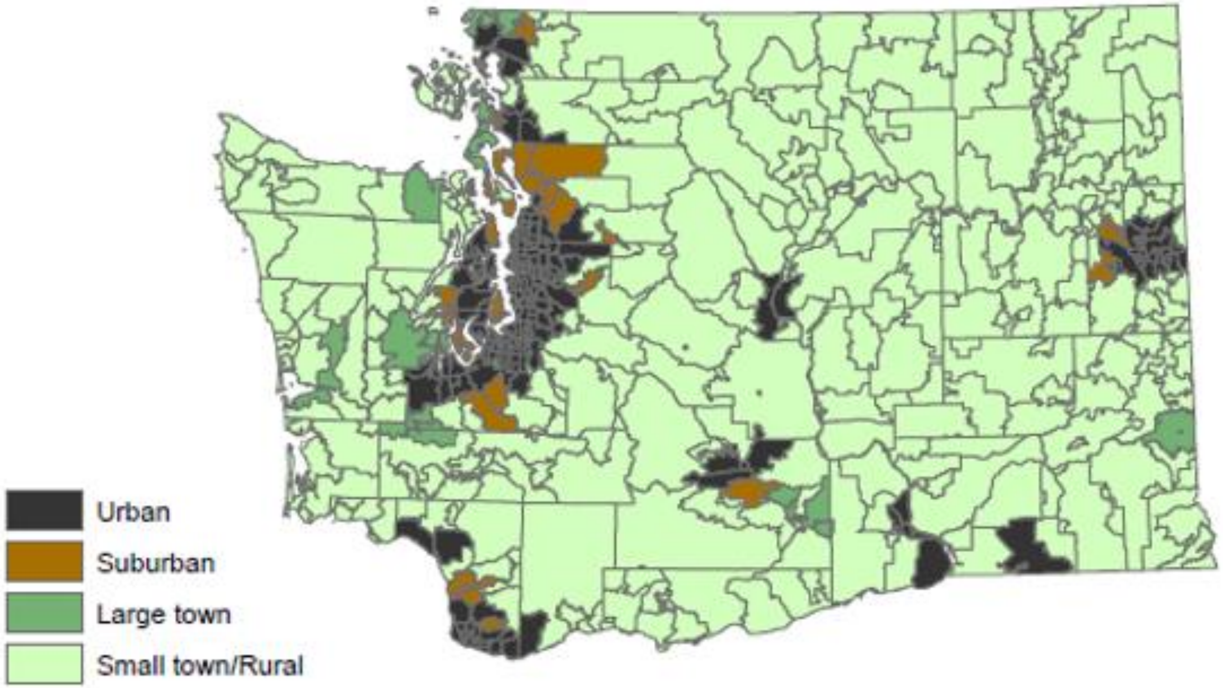
“Ninety percent of hospitals with palliative care are in urban areas. Only 17% of rural hospitals with 50 or more beds report palliative care programs.”

https://reportcard.capc.org/
Accessed 10/22/2021

Of the total Washington State land area: 96.4 % is rural and 3.6% is urban (2010 Census-Reviewed 2021)

11-16% of the population is rural (varies with definition used)

Four-tier Rural Urban Classification by ZIP code



Note: Geography is classified using a modified scheme, based on Census 2010, Rural Urban Commuting Area (RUCA) codes; into urban (e.g., Seattle), suburban (e.g., North Bend), large town (e.g., Oak Harbor), and small town/rural (e.g., Goldendale).

What is Palliative Care?

What is palliative care?

Washington Rural Palliative Care Initiative

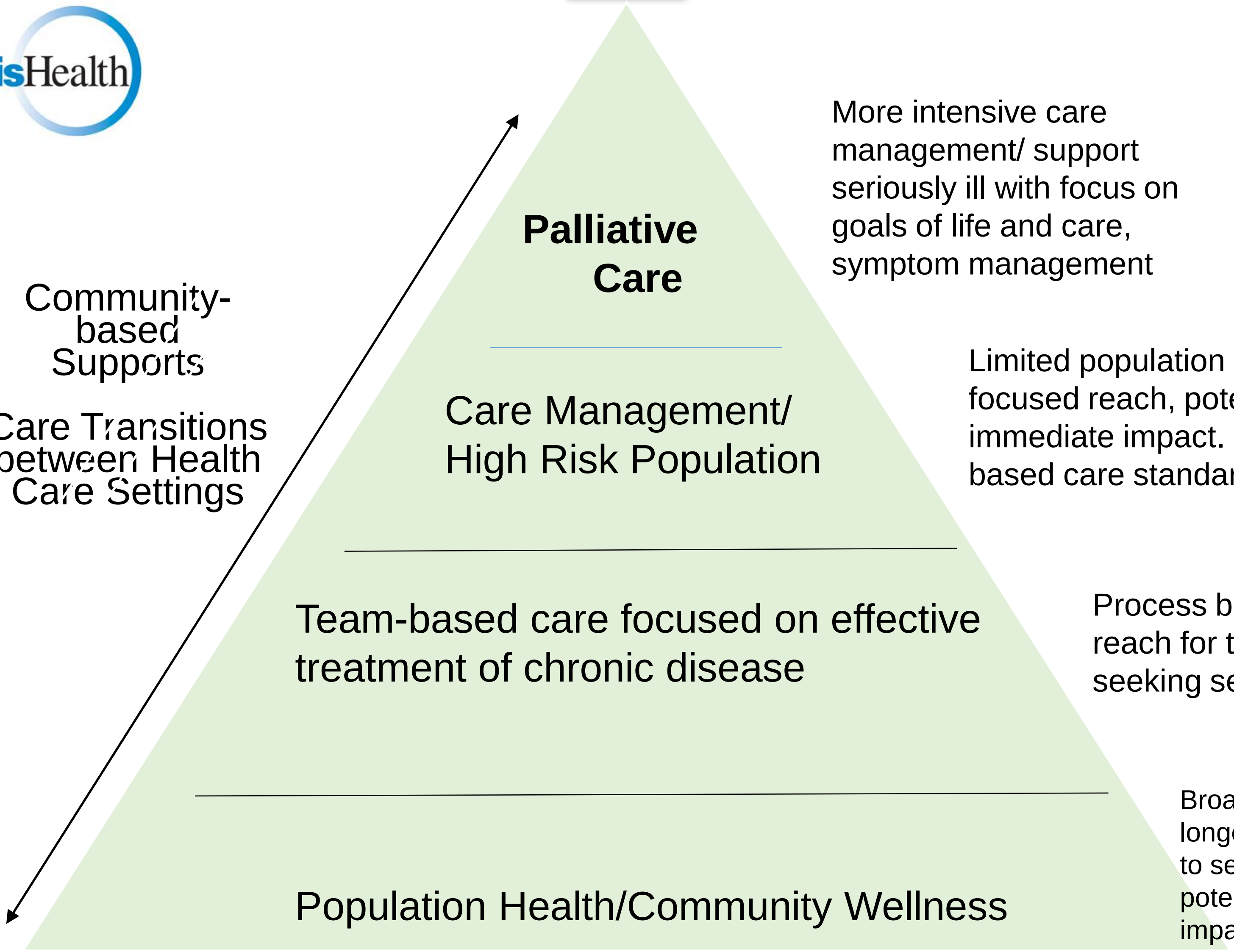
Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.

Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care

Palliative Care Bow Tie Model

Piper Hawley, Bmed, FRPC
University of British Columbia, Head of Palliative Care Division

Palliative Care in Alignment with other Population Health Services



Community-based Supports

Care Transitions between Health Care Settings

Palliative Care

More intensive care management/ support seriously ill with focus on goals of life and care, symptom management

Care Management/ High Risk Population

Limited population - more focused reach, potential for immediate impact. Evidence based care standards

Team-based care focused on effective treatment of chronic disease

Process based, broad reach for those seeking services.

Population Health/Community Wellness

Broadest reach, longest timeframe to see results (but potentially biggest impact)

Formula for program development

- Community data and goals/Stakeholder input/Community-based team
- Access to national standards, intervention models, and resources
- Participation in a learning community of peers
- Structured process for development/implementation (Facilitated Community Team Planning)

=

Custom-designed, community-based program

Adapted from StratisHealth

Community capacity development theory (CCDT)

- Communities tackle problems through collective problem solving
- Change happens by enhancing existing capacities
- Approach is strength based
- Requires leadership, broad participation, learning over time

Adapted from

StratisHealth

Why this approach works in rural communities

- Rural communities know their strengths and weaknesses
- Rural communities know their culture best
- Rural providers know their patients
- Rural communities can identify and tailor solutions that best fit their unique situation

Thc StratisHealth or use of this slide

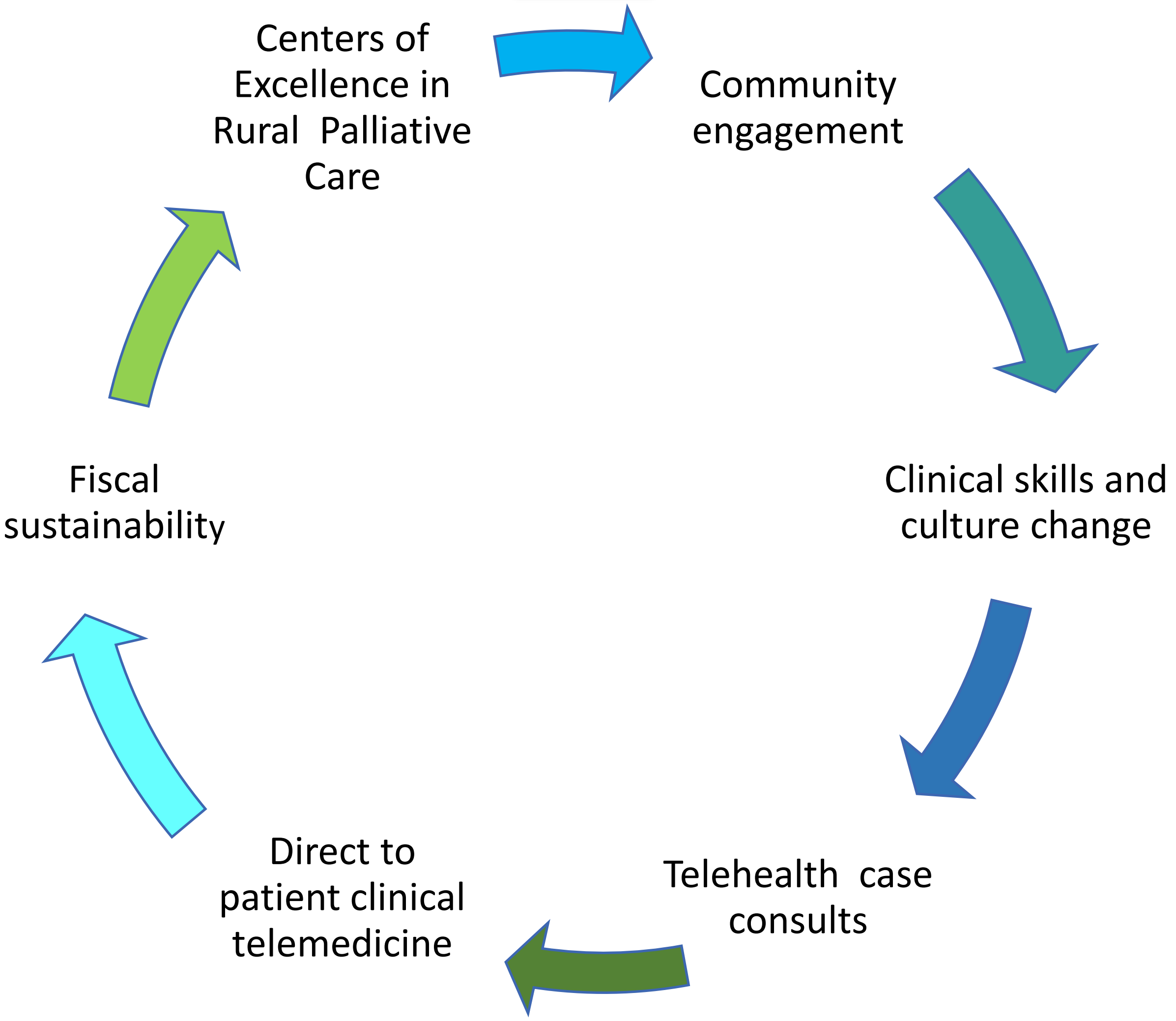
What does a rural palliative care program look like?

- Wide variation in structure and focus.
- Inter-disciplinary teams sometimes multi-organization.
- Dynamic issues of capacity to manage when workforce fluctuates.
- Windshield time for home visits can be significant, for example Okanogan County is frontier, and larger than Maryland, Rhode Island and Delaware combined.
- Moving forward, telehealth will be integral.

Washington Rural Palliative Care Initiative Objectives

- Assist rural health systems and communities to integrate palliative care in multiple settings, to better serve patients with serious illness in rural communities.
- Decrease transfers to urban tertiary services.
- Move upstream to serve patients with serious illness earlier in their experience of illness.
- Develop funding models for sustainable services

Washington State Rural Palliative Care Initiative



Centers of Excellence in Rural Palliative Care

Community engagement

Clinical skills and culture change

Telehealth case consults

Direct to patient clinical telemedicine

Fiscal sustainability

Learning Action Network (LAN)

- Learning and Action Networks are designed as an ongoing cohort dedicated to deep shared learning about a specific concept .
- LANs provide a forum for bringing together healthcare teams, and other supportive partners around an evidence-based agenda to achieve wide-scale improvement.
- **Peer to peer learning and support**

Community Engagement

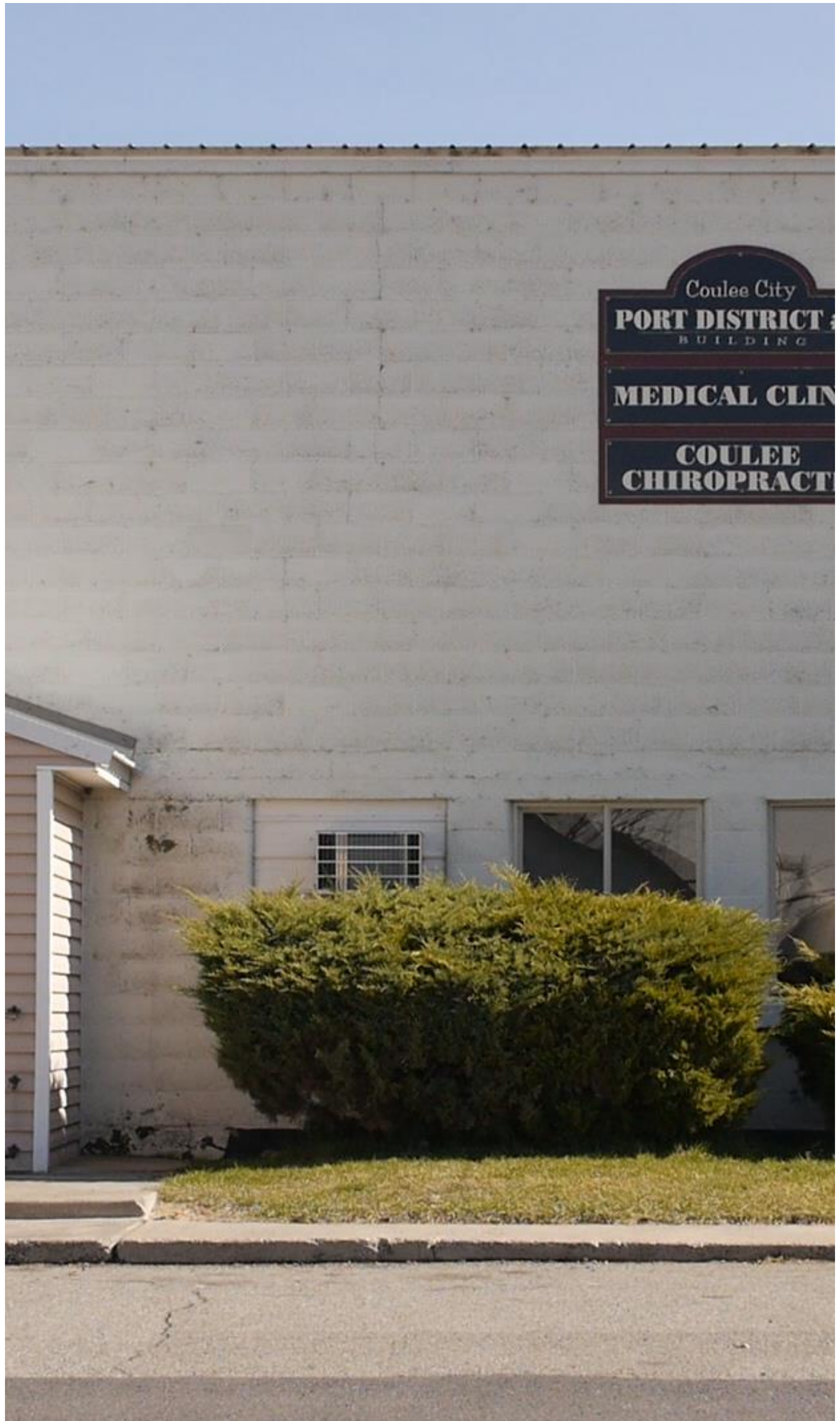
- Identify champions
- Coaching on how to start and the development path
- Community Asset and Gap Analysis
- Community Action Plan- more than healthcare
- Tools for public and clinical team education

Clinical skills and culture change

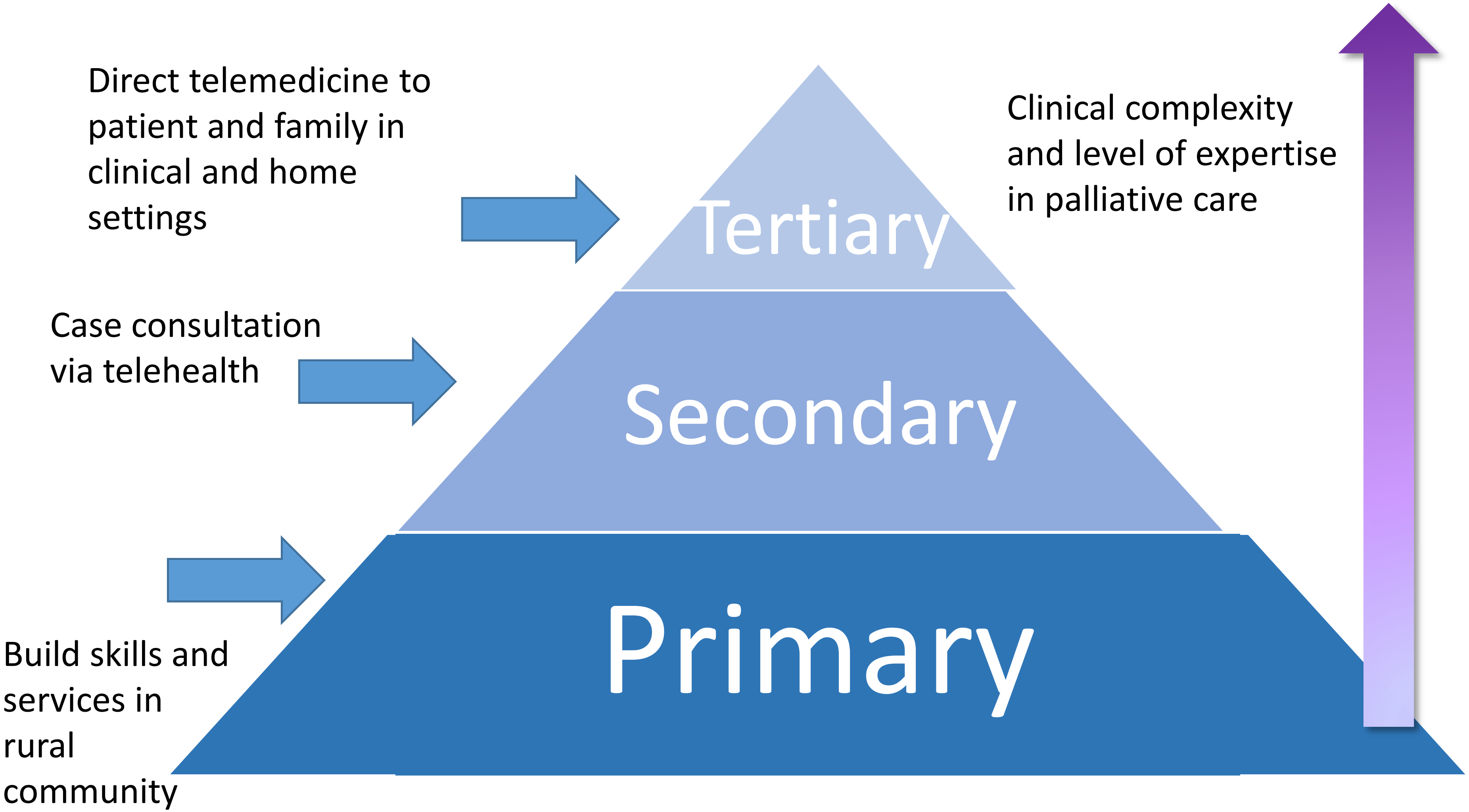
[Ariadne labs serious illness care](#)

[Cambia Center for Excellence in Palliative Care-University of WA](#)

[VitalTalk](#)



Levels of expertise in palliative care



Direct telemedicine to patient and family in clinical and home settings

Case consultation via telehealth

Build skills and services in rural community

Clinical complexity and level of expertise in palliative care

Disparities beget disparities

- Broadband and satellite coverage gaps in rural accentuate rural inequities in access.
- Covid-19 instigated WA Department of Commerce to build out 300 new hotspots.

Lessons learned

- Serious Illness communication skills training creates confidence.
- Close collaboration with the member organization(s) for hospice, and home health is critical.
- Highly likely that eligible patients will outstrip capacity-start small, very small.

Lessons learned

- Early adopters might be the people who have too many top priorities for transformation.
- Disruption from leadership turnover can jeopardize or stall fledgling services.
- Telehealth case consults are of large value to our cohort teams
- Clinical telemedicine direct to patients is here to stay; but different than we envisioned.

Dementia Action Collaborative
Washington State

Dementia Road Map:
A Guide for Family and Care Partners

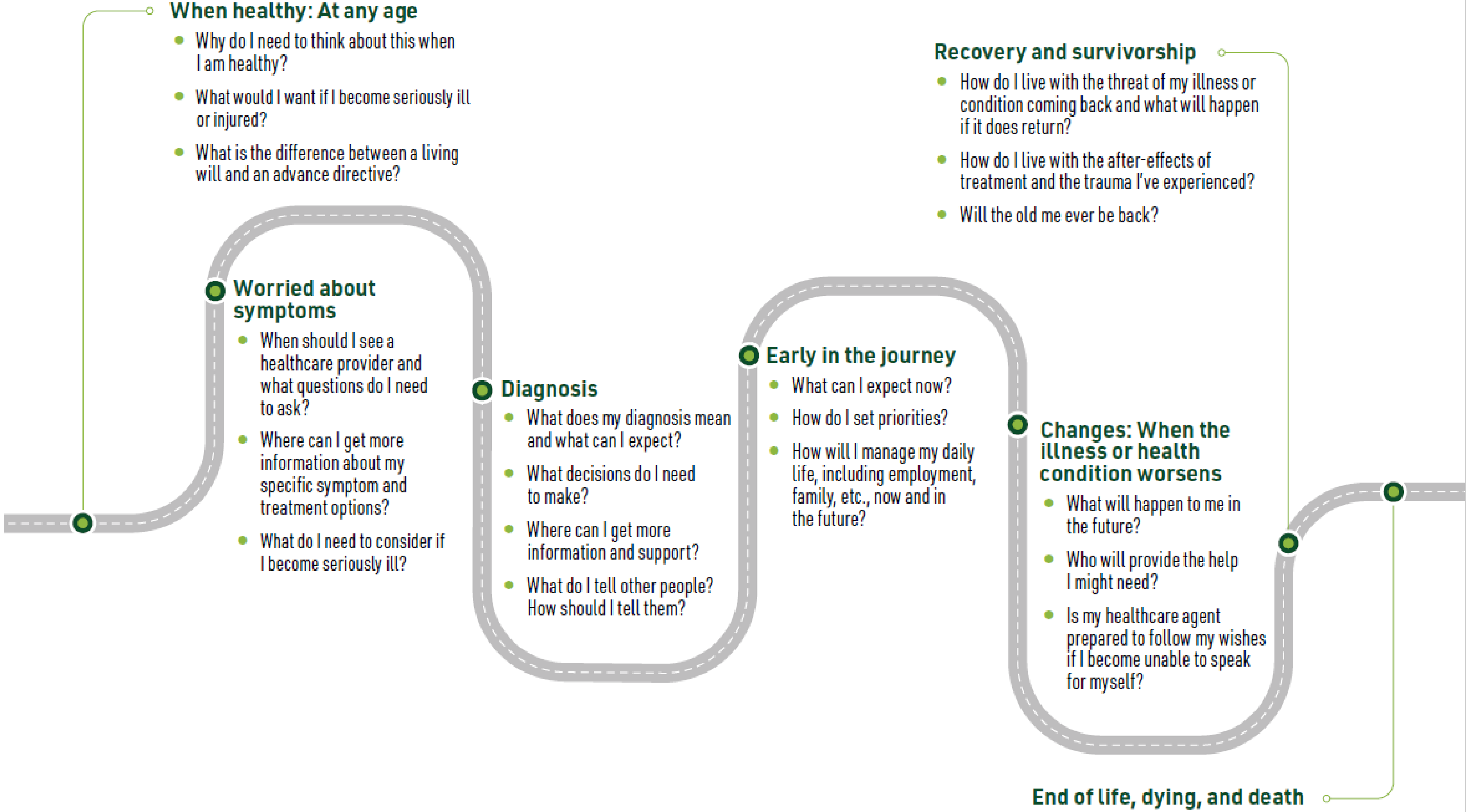
https://www.dshs.wa.gov/sites/default/files/ALTSA/stakeholders/documents/AD/Dementia%20Road%20Map%20-%20A%20Guide%20for%20Family%20and%20Care%20Partners.pdf

PALLIATIVE CARE ROAD MAP

A GUIDE for living with serious illness and conditions for patients and those who care for them

PALLIATIVE CARE ROAD MAP

QUESTIONS YOU MAY HAVE ALONG THE WAY



When healthy: At any age

- Why do I need to think about this when I am healthy?
- What would I want if I become seriously ill or injured?
- What is the difference between a living will and an advance directive?

Worried about symptoms

- When should I see a healthcare provider and what questions do I need to ask?
- Where can I get more information about my specific symptom and treatment options?
- What do I need to consider if I become seriously ill?

Diagnosis

- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

Early in the journey

- What can I expect now?
- How do I set priorities?
- How will I manage my daily life, including employment, family, etc., now and in the future?

Changes: When the illness or health condition worsens

- What will happen to me in the future?
- Who will provide the help I might need?
- Is my healthcare agent prepared to follow my wishes if I become unable to speak for myself?

Recovery and survivorship

- How do I live with the threat of my illness or condition coming back and what will happen if it does return?
- How do I live with the after-effects of treatment and the trauma I've experienced?
- Will the old me ever be back?

End of life, dying, and death

- How will I know I am nearing the end of my life?
- What are my ideas about a good death?
- How can I make sure my wishes about the end of my life are expressed and followed?

DIAGNOSIS

You may be wondering

- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

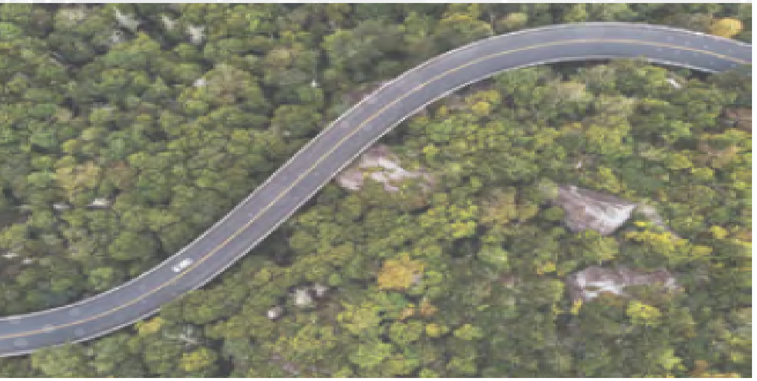
What to expect

- You may not fully understand what your condition means. You might feel embarrassed about things that are confusing and be reluctant to ask questions.
- You are likely to experience many different emotions.
- You may wonder about the future, what will happen next, how the illness will progress, and what will be in your control to influence.
- You may realize your needs are no longer met by a member of your present healthcare team. It can be hard to make a change in your care team, but can make a large difference in trust and well-being.

What you can do

- Gather information and ask questions. You may want a second opinion.
- You can decide how much privacy is important to you and who will have access to what information. Decide who needs to be with you to hear news and help make significant decisions. Consider which family and friends can be "real" with you and offer a sense of ease.
- Know you don't have to do it alone. Put together a team and a list of specific actions where you will allow others to help you, for example rides to appointments, walking a dog, researching resources, or picking up prescriptions.
- You have the right to understand the risks and benefits of treatment including non-traditional or complementary approaches. You also have the right to understand the risks and benefits of not choosing a particular treatment.

> "Life is choices and they are relentless."
>
> — Atul Gwande



To download the PDF or order printed copies at no charge:

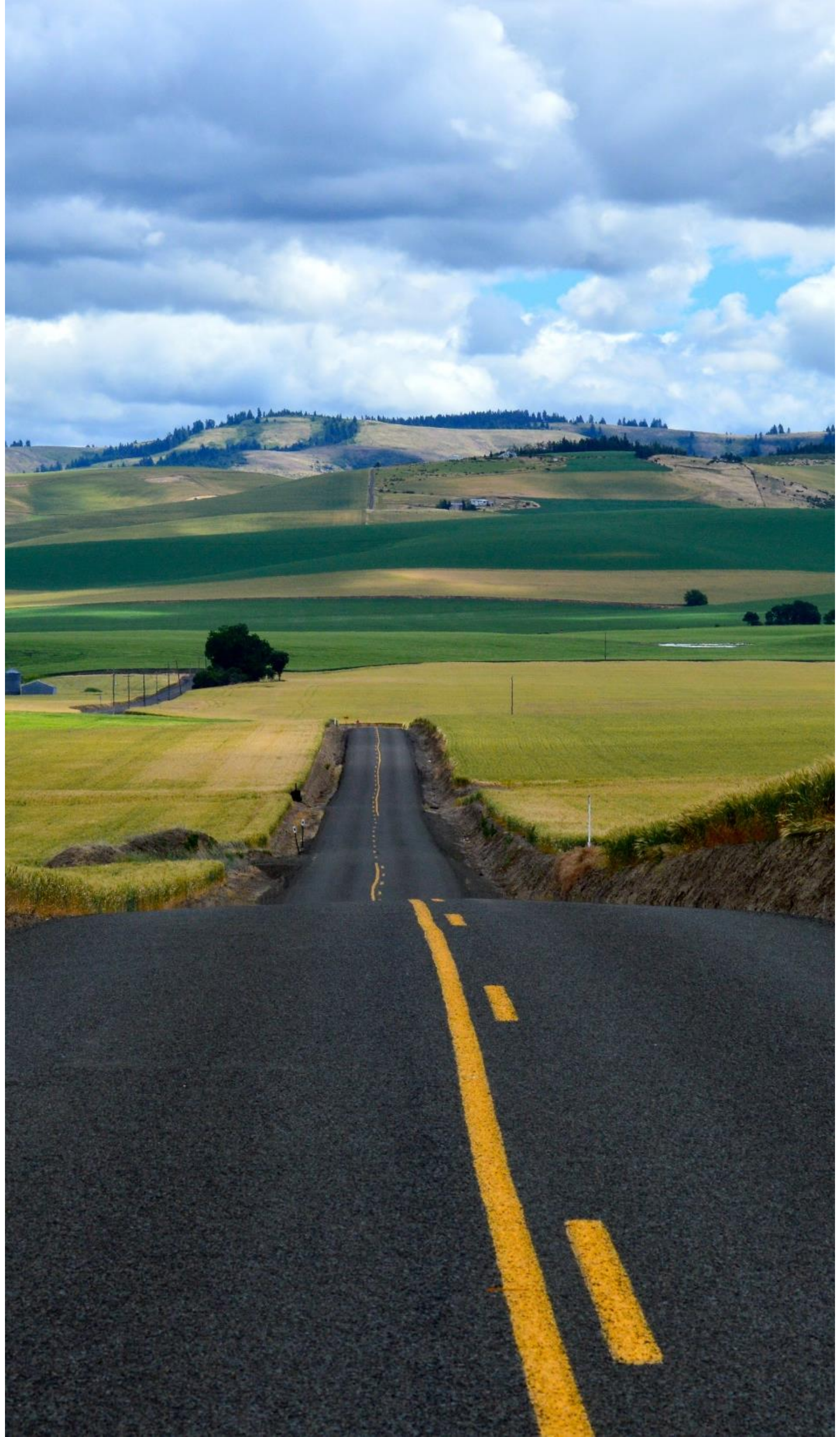
https://www.doh.wa.gov/forpublichealthandhealthcareproviders/ruralhealth

OR

https://waportal.org/partners/home/washington-rural-palliative-care-initiative

Getting started in your state: rural palliative care

- Environmental scan-statewide
- Bring together an advisory team; palliative care experts, rural health leaders, telehealth experts, medical schools, nursing programs
- Build a model to support developmental work for rural healthcare systems and communities
- Learning Action Network is an effective method
- Integrate QI rapid cycle improvement
- Take the long view



Two rural initiatives

Minnesota-Stratis Health- over 20 rural communities offering palliative care

Washington Rural Palliative Care Initiative

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Washington State Department of
Health