

# Building a Statewide Network for Rural Palliative Care



Lyn Ceronsky DNP, GNP, FPCN Palliative Care  
Consultant and Nurse Practitioner

Nancy E Joyner MS, CNS-BC, APRN, ACHPN®

Palliative Care Outreach Specialist- UND

## Land Acknowledgement Statement

“Today, the University of North Dakota rests on the ancestral lands of the Pembina and Red Lake Bands of Ojibwe and the Dakota Oyate - presently existing as composite parts of the Red Lake, Turtle Mountain, White Earth Bands, and the Dakota Tribes of Minnesota and North Dakota.

We acknowledge the people who resided here for generations and recognize that the spirit of the Ojibwe and Oyate people permeates this land. As a university community, we will continue to build upon our relations with the First Nations of the State of North Dakota - the Mandan, Hidatsa, and Arikara Nation, Sisseton-Wahpeton Oyate Nation, Spirit Lake Nation, Standing Rock Sioux Tribe, and Turtle Mountain Band of Chippewa Indians.”

## Objectives

### Identify

**Identify the role of networks related to palliative care in rural communities.**

### Describe

**Describe the examples of palliative care networks.**

### Recognize

**Recognize the challenges of creating a statewide palliative care network in North Dakota.**

## Dave and Mary Johnson

- An 84-year-old couple, married 50 years, live in a small North Dakota town, adult children live in California. Dave has afib, COPD, DM, and worsening heart failure. Mary has metastatic colon cancer with worsening pain, but her overall quality of life is good.
- The primary care physician asks “what services do we have to help support this couple? I would not be surprised if either died within the next two years.”





## The Pillars of Palliative Care

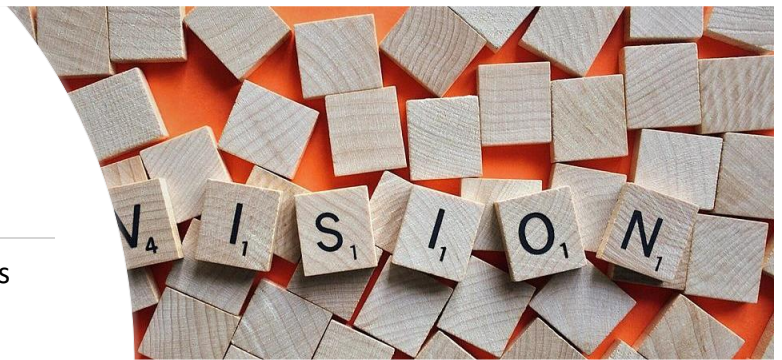
- Pain and symptom management: assess, treat, evaluate
- Psychosocial and spiritual support (patient and family)
- Information and support to make decisions that reflect goals and values as illness progresses
- Ensure continuity of the care plan

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## The Vision for Rural Palliative Care

Quality rural palliative care programs across North Dakota would

- Provide care consistent across disease trajectory in all settings (community-at home, long term care, hospital, clinics)
- When and where patients/families need it
- Integrate with health care system (not separate) and
- Meet or exceed quality standards



## What is a Rural Health Network?

“a group of three or more rural health providers and/or other stakeholders that join forces to address mutually agreed-upon needs in the community. “

“their purpose may be broader and may evolve over time as the community's needs shift. Network members may include a variety of participants, including (but not limited to) healthcare providers, nonprofit organizations, government agencies, public health professionals, educational providers, and private organizations.”



(RHIFHub website)

## Poll Questions

1. How would you network with other rural palliative care communities?
2. What are some advantages of networking in your community?

## Functions of Effective Networks

- Provide **valuable information** not widely known
- **The Human Connection:** Connects you to others
- **Amplify influence** by connecting you to individuals whose interests align with your own.



## Qualities of Successful Networks

- Effective Leadership
- Cross organizational and professional boundaries
- Complement services and resources
- Creative and collaborative
- Willing to engage in mutual problem solving

(Ceronsky 2018)

## POLL questions

3. What are your challenges of networking?
4. Are you currently on the the ND Palliative Care Taskforce email list?



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## Positive Rural Attributes

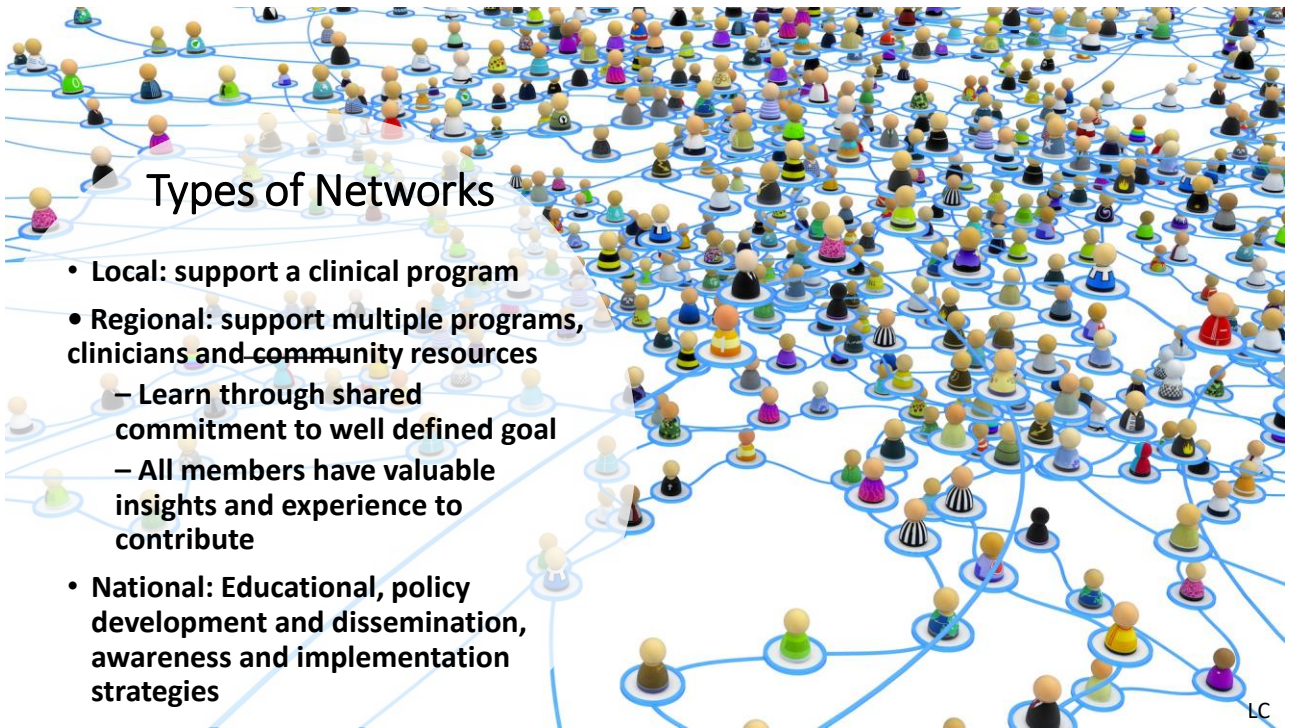
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- Commitment to people in our communities
- Experience in designing solutions to problems
- Wear many hats
- Know resources: people, organizations, culture
- Others



## Challenges of Creating a North Dakota Statewide Palliative Care Network

- Geographic distances and isolation
- Aging of population
- Economic and cultural disparities
- Cost of health care continues to grow



Statewide

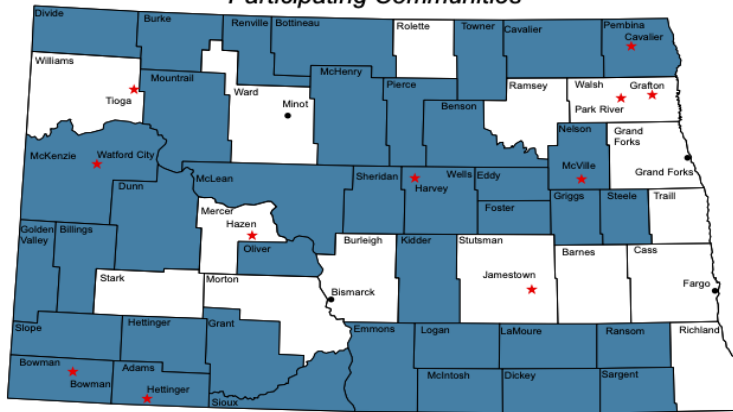




# North Dakota's Rural Community-based Palliative Care Participating Communities

(<https://ruralhealth.und.edu/projects/community-palliative-care>)

## North Dakota Rural Community-Based Palliative Care Project Participating Communities



38 of 53 North Dakota counties designated as frontier\*  
\*Less than 7 persons per square mile

Source: U.S. Census Bureau, ACS 2018  
5-Year Estimates  
Created by the North Dakota Healthcare  
Workforce Group on 4/2022



Palliative Care

**Center for Rural Health  
University of North Dakota**

This model is committed to addressing the needs of the most vulnerable populations by equipping rural community providers with the right knowledge, at the right place, at the right time to locally deliver high-quality care.

Organizing Palliative  
Care for Rural  
Populations  
TeleECHO

**Final Clinic**

**Growing and  
Sustaining a Rural  
Palliative Care  
Network**  
July 26, 2022

<https://ruralhealth.und.edu/projects/project-echo/topics/palliative-care>

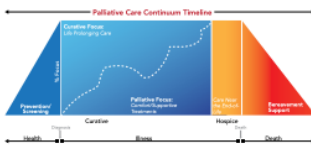
# North Dakota Palliative Care Task Force

“committed to improving the quality of life of those facing serious health conditions by promoting patient-centered palliative care and improving access to services.”

## Palliative Care or Hospice Care?

**What is Palliative Care?**  
Palliative care is a specialized medical care for people with serious illnesses. It is appropriate at any stage of any illness, a serious illness and can be provided together with curative treatment. Palliative care improves quality of life by addressing the physical, psychological, emotional, cultural, social, and spiritual needs of patients and families. It offers treatment of pain and other symptoms, relief from worry and distress of disease, clear communication about goals of care, and psychosocial care during illness resolution. It offers palliative care across treatment settings and support for family/caregivers and offers a sense of safety in the healthcare system. Palliative care is delivered by a team of clinicians, nurses and other specialists who work with the patient's other clinicians to provide an extra layer of support.

**What is Hospice Care?**  
Hospice care is a team approach to expert medical care for individuals who have a life-limiting illness. With a focus on comfort, the team develops a plan of care tailored to each individual's needs and goals. It includes pain and symptoms management, personal care, emotional and spiritual support, and grief support for the each individual's loved ones. All of hospice is palliative care, but not all of palliative care is hospice.



For more information:  
Nancy Joplin, MS, CNBC, APRN, ACHPN  
504.776.8822 | njoplin@nd.gov

Center for Rural Health  
University of North Dakota  
504.776.8822 | centerforruralhealth@und.edu

Palliative Care Continuum Diagram modified from:  
Lynn J. Grune, MD, MEd, FACP, FRCPC, FRCPC (P) | The New York University Center for Palliative Care, Meeting Report: November/December 2008, 8-16  
© 2008, 2010, 2012, 2014, 2015, 2016, 2017, 2018, 2019, 2020, 2021, 2022, 2023, 2024, 2025, 2026, 2027, 2028, 2029, 2030, 2031, 2032, 2033, 2034, 2035, 2036, 2037, 2038, 2039, 2040, 2041, 2042, 2043, 2044, 2045, 2046, 2047, 2048, 2049, 2050, 2051, 2052, 2053, 2054, 2055, 2056, 2057, 2058, 2059, 2060, 2061, 2062, 2063, 2064, 2065, 2066, 2067, 2068, 2069, 2070, 2071, 2072, 2073, 2074, 2075, 2076, 2077, 2078, 2079, 2080, 2081, 2082, 2083, 2084, 2085, 2086, 2087, 2088, 2089, 2090, 2091, 2092, 2093, 2094, 2095, 2096, 2097, 2098, 2099, 2100, 2101, 2102, 2103, 2104, 2105, 2106, 2107, 2108, 2109, 2110, 2111, 2112, 2113, 2114, 2115, 2116, 2117, 2118, 2119, 2120, 2121, 2122, 2123, 2124, 2125, 2126, 2127, 2128, 2129, 2130, 2131, 2132, 2133, 2134, 2135, 2136, 2137, 2138, 2139, 2140, 2141, 2142, 2143, 2144, 2145, 2146, 2147, 2148, 2149, 2150, 2151, 2152, 2153, 2154, 2155, 2156, 2157, 2158, 2159, 2160, 2161, 2162, 2163, 2164, 2165, 2166, 2167, 2168, 2169, 2170, 2171, 2172, 2173, 2174, 2175, 2176, 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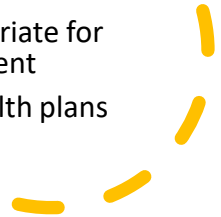




## California Health Care Foundation

### California Health Care Foundation

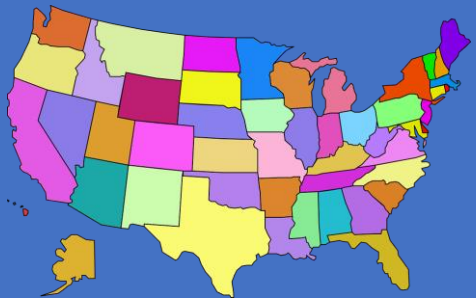
- Health Plans teamed with Palliative Care Provider Agencies
- Developed criteria for people appropriate for palliative care, processes for enrollment
- Incorporated data analytics from health plans
- Created capacity in clinical staff



<https://www.chcf.org/topic/serious-illness-end-of-life-care/>

LC

Regional/National



LC

Palliative  
Care  
Network of  
Wisconsin  
PC Now

Supports the growth of palliative care services in Wisconsin through

- Education
- Systems Change
- Advocacy: health care policy, regulations and legislation



<https://www.mypcnow.org/>

LC

National  
Hospice and  
Palliative  
Care  
Organization

- **Advancing healthcare with a model that works**
- NHPCO enhances and expands access to care that addresses holistic health and the well-being of communities.



<https://www.nhpc.org/>

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## Hospice and Palliative Nurses Association

- Advance nursing expertise in hospice and palliative care through education, advocacy, leadership, and research.
- Support hospice and palliative research, education, and leadership development to advance expert nursing care.
- Advance expert care in serious illness through state-of-the-art certification of continuing competency in hospice and palliative care and research.

<https://hpna.advancingexpertcare.org/>

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## Center to Advance Palliative Care

Provides essential tools, training, technical assistance, and connection for all clinicians caring for people with a serious illness



<https://www.capc.org/>

## National Academy for State Health Policy

Provides guidance in developing a framework for how states, as agents of change, can foster access to quality palliative care services



<https://www.nashp.org/palliative-care/>

## National POLST



- At the national level, it is simply called **POLST: Portable Medical Orders**, or POLST for short
- Honoring the wishes of those with serious illness and frailty.
- Organizes the effort to standardize the POLST process, form and education throughout the U.S., since POLST varies from state to state.

<https://polst.org/>

# ARIADNE Serious Illness Program



- Redesigns care so that knowing and honoring patients' priorities becomes the norm, not the exception.
- System-level care delivery model created by a team of palliative care experts at Ariadne Labs.
- Goal is for every seriously ill patient to have more, better, and earlier conversations with their clinicians about their goals, values, and priorities that will inform their future care.

Serious Illness Conversation Guide	
CONVERSATION FLOW	
PERSON-CENTERED LANGUAGE	
1. <b>Set up the conversation</b> Introduce purpose Prepare for future decisions Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — <b>is this okay?</b> "
2. <b>Assess understanding and preferences</b>	"What is your <b>understanding</b> now of where you are with your illness?" "How much information about what is likely to be ahead with your illness would you like from me?"
3. <b>Share prognosis</b> Share prognosis Frame as "with worry" "Hope-worry" statement Allow silence, explore emotion	"I want to share with you my <b>understanding</b> of where things are with your illness." "Disruption: "It can be difficult to predict what will happen with your illness. <b>Hope</b> you will continue to live well for a long time but I'm <b>worried</b> that you could get sick quickly, and I think it is important to prepare for that possibility." OR Time: "With us were not in this situation, but I'm <b>worried</b> that time may be so short for... [insert as range, e.g. days to weeks, weeks to months, months to a year]" OR Function: "I <b>hope</b> that this is not the case, but I'm <b>worried</b> that this may be as strong as you will feel, and things are likely to get more difficult."
4. <b>Explore key topics</b> Goals Fears and worries Sources of strength Critical abilities Identity Family	"What are your most important <b>goals</b> if your health situation worsens?" "What are your <b>biggest fears and worries</b> about the future with your health?" "What gives you <b>strength</b> as you think about the future with your illness?" "What <b>abilities</b> are so critical to your life that you can't imagine living without them?" "If you become sicker, <b>how much</b> are you <b>willing to go through</b> for the possibility of gaining more time?" "How much does your <b>family</b> know about your priorities and wishes?"
5. <b>Close the conversation</b> Summarize Make a recommendation Check in with patient Address commitment	"I've heard you say that... is really important to you. Keeping that in mind, and what we know about your illness, I <b>recommend</b> that we... This will help us make sure that your treatment plan reflects what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. <b>Document your conversation</b>	
7. <b>Communicate with key clinicians</b>	

<https://www.ariadnelabs.org/serious-illness-care/>

## Coalition to Transform Advanced Care

- Dedicated to improving the lives of underserved and under-resourced people impacted by serious illness.
- Work with regulators, legislators, advocates, and funders to craft policies that ensure more equitable, comprehensive, accessible care and support for patients, families and unpaid caregivers
- An unbiased source of expertise on serious illness and a respected convener of more than 190 organizations that share our vision of a healthcare system that serves patient needs and honors their dignity.



<https://www.thectac.org/>



# Palliative Care Network

- **MISSION**

- Palliative Care Network's mission is to provide a digital platform aimed at promoting palliative care education and collaboration globally.

- **VISION**

- Palliative Care for Everyone, Everywhere.



<https://palliativecarenetwork.com/>

## Final Thoughts



## Sustainability for You

- Self Care is a key aspect for you and for your programs
- Consider the role of a network in supporting sustainability
- Build this in



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## Networking Case Study

- Small home care organization in rural state
- Motivated to begin palliative home care program
- Leadership and clinical role changes
- Being part of a network allowed staff new to the organization to access tools ( ex: palliative care plan), receive mentoring and continue in role despite challenges

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## Back to Dave and Mary Johnson



- Dave and Mary have access to a palliative care program that delivers services through home care and their primary care clinic. Through these services, both participate in serious illness conversations. Their wishes are documented in their medical record and shared with their adult children.
- The palliative care program helps them access volunteer services to check on their well being weekly.
- Eventually, both are admitted to hospice.

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## Conclusion

- Palliative care networking can offer significant benefits in rural communities.
- Palliative care networks span local, state, regional, national and international scope
- Strategies can be created to to meet the challenges for North Dakota palliative care

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## Additional References/Resources

- [Improving Access to Palliative Care in Rural Communities](#) (CAPC)
- [Rural Hospice and Palliative Care \(RHHub\)](#)
- [Creating a Rural Palliative Care Network Forging the Future of Palliative Care \(ppt Ceronsky, 2018\)](#)
- [Palliative Care Network](#)
- “Home on the Range: Plans and Providers Team Up to Bring Palliative Care to Rural Californians” 5.13.20. [www.chcf.org](http://www.chcf.org). downloaded April 17, 2022