Building a Rural, Community-Based Palliative Care Program In North Dakota

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Objectives

- Describe use of an asset and gap analysis tool to establish foundation for community-based rural palliative care.
- Identify how palliative care can be provided in a rural setting.
- Explain how to create and implement an action plan for palliative care.

Palliative Care Definition

- Interdisciplinary care delivery system designed for patients, their families and caregivers
- Beneficial at any stage of a serious illness
- Anticipates, prevents, and manages physical, psychological, social, and spiritual suffering to optimize quality of life
- Delivered in any care setting through the collaboration of many types of care providers
- Improves quality of life for both the patient and the family through early integration into the care plan

- 2018,National Consensus Project for Quality Palliative Care

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NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE
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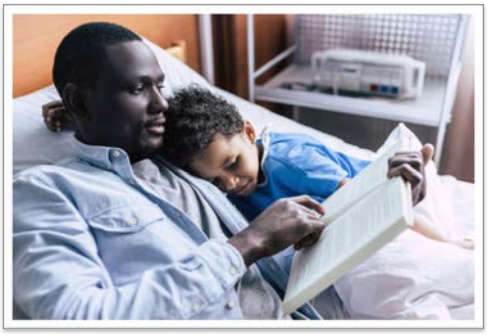
Key Concepts

- Person-and family-centered approach to care
- Inclusive of all people living with serious illness, regardless of setting, diagnosis, age or prognosis
- A responsibility of all clinicians and disciplines caring for people living with serious illness



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Serious Illness

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 their caregiver.*

*Kelley, AS, Bollens-Lund, E. Identifying the population with serious illness: the "denominator" challenge. Journal of Palliative Medicine. Volume: 21 Issue S2: March 1, 2018.

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Palliative Care Is Needed Everywhere

- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment.
- People may need palliative care in hospitals, in the community, in nursing facilities

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Community is Person-Centric

"Community" is defined:

- by the person living with serious illness
- as a lens through which their needs are assessed

- National Consensus Project Directions Summit

Strategic
June 2017

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Eight Domains of Palliative Care

1. Structure and process of care
2. Physical aspects of care
3. Social aspects of care
4. Psychological aspects of care
5. Spiritual aspects of care
6. Cultural aspects of care
7. Care of the patient at end of life
8. Ethical and legal aspects of care

National Consensus Project Clinical Practice Guidelines PDF

Specialty Palliative Care and Primary Palliative Care

- Specialist providers: complete fellowships, achieve certification; almost total focus in palliative care
- Primary palliative care providers: skilled in symptom management, communication, psychosocial and spiritual support, transitions of care. Processes are in place to support their work.

Developing a Palliative Care Program

Principles of Developing Community Based Palliative Care

- Assess need: talk with stakeholders
- Understand local environment
- Pilot program
- Ensure financial support
- Collect program data
- Coordinate care
- Assure quality

Center to Advance Palliative Care

First Step: Needs Assessment

- Identifies gap between current and needed palliative care services
- Confirms your motivation for starting a program
- Describes priorities of stakeholders to guide program development

Asset and Gap Analysis

- Questions assessing the current level of services in your community and prioritization of improvement opportunities.
- Services are currently available in your community and if they are provided directly by an organization represented on your Community Team.

Adult/geriatric nurse practitioner		
Bereavement care (apart from hospice)		
Case management for chronic disease		
Community health workers		
Home care (supportive care)		
Home health services (medical care)		
Hospice care		
Medical social worker		
Pain management consultation		
Parish nursing		
Pastoral care/chaplaincy		
Respite care for family caregivers apart from hospice		
Support groups, such as caregiver support groups or grief support groups		
Transportation		
Other (please specify):		

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Asset and Gap Analysis

Palliative Care Core Processes	Rate level of expertise None		Moderate		High
Bereavement care (apart from hospice)	0	1	2	3	4
Continuity of care/care management	0	1	2	3	4
Family conferencing with goals of care discussions	0	1	2	3	4
Hospice	0	1	2	3	4
Interdisciplinary team care	0	1	2	3	4
Pain management consultation	0	1	2	3	4
Staff education on palliative care	0	1	2	3	4
Symptom management (other than pain)	0	1	2	3	4

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Opportunities for improving care	Rate level of opportunity to improve care None		Moderate		High
Advance directives assistance	0	1	2	3	4
Alternatives to hospital admission at end of life	0	1	2	3	4
Chronic disease case management	0	1	2	3	4
Comprehensive care plan for those requiring comfort care	0	1	2	3	4
Home visits as part of care coordination (not part of home health services or home care)	0	1	2	3	4
Pain management consultation	0	1	2	3	4
Providing education to families/caregivers about caring for people with advanced illness	0	1	2	3	4
Providing education to staff about caring for people with advanced illness	0	1	2	3	4
Psychosocial support for patient/family	0	1	2	3	4
Referrals to hospice, home health services, home care, or other placements	0	1	2	3	4
Spiritual care	0	1	2	3	4
Symptom management consultation	0	1	2	3	4
Transitioning the plan of care between hospital, nursing home, home care, etc.	0	1	2	3	4
Other (please specify):	0	1	2	3	4

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Profession	Palliative care/hospice board certification (physicians & nursing)	EPEC trained (Education in Palliative and End of Life Care) – for physicians	ELNEC trained (End of Life Nursing Education Consortium)	Other palliative care/hospice training or education e.g., PCLC (Palliative Care Leadership Center) or clinical training
Chaplain				
Nurse				
Nursing assistant				
Nurse practitioner				
(please specify):				

•In general, what is your perception of the knowledge of palliative care among health ca

Professional	Rate perceived level of knowledge None	1	Moderate 2	3	High 4
Administration	**0**	**1**	**2**	**3**	**4**
Chaplain	**0**	**1**	**2**	**3**	**4**
Medical (MD, PA, NP)	**0**	**1**	**2**	**3**	**4**
Nursing	**0**	**1**	**2**	**3**	**4**
Pharmacy	**0**	**1**	**2**	**3**	**4**
Social work	**0**	**1**	**2**	**3**	**4**
Other clinical (PT, OT, SLP, etc.)	**0**	**1**	**2**	**3**	**4**

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Educational need areas	Rate need for Community Team None		Moderate		High
Advanced care planning	0	1	2	3	4
Ethical dilemmas in palliative care	0	1	2	3	4
Grief counseling	0	1	2	3	4
Health insurance literacy (e.g., understanding coverage and costs to help patients and families with decision making)	0	1	2	3	4
Interdisciplinary teamwork (e.g., care coordination)	0	1	2	3	4
Involving patients/families in care decisions	0	1	2	3	4
Pain assessment and management	0	1	2	3	4
Providing emotional support to patients/families	0	1	2	3	4
Strategies to inform patient/family of diagnosis/prognosis	0	1	2	3	4
Symptom management (other than pain management)	0	1	2	3	4
Understanding cultural beliefs/values	0	1	2	3	4
Understanding family dynamics/ support systems	0	1	2	3	4
Understanding local community resources	0	1	2	3	4
Understanding philosophy of palliative care	0	1	2	3	4
Understanding spiritual needs of patients/families	0	1	2	3	4
Other (please specify):	0	1	2	3	4

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Potential barrier	Rate ability to affect your community None		Moderate		High
Community awareness of palliative care	0	1	2	3	4
Human resources to provide services	0	1	2	3	4
Lack of clinician knowledge and experience about palliative care	0	1	2	3	4
Coordination of care between providers/ settings	0	1	2	3	4
Medical staff commitment/buy-in to palliative care	0	1	2	3	4
Reimbursement	0	1	2	3	4
Other (please specify):	0	1	2	3	4

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Community Information

Name of Community (if applicable):

Location (City, State):

Team members/organizations participating in completion of this survey	
Name	Organization

Second Step: Decide Program Focus and Structure

- Specialty services
  - Where, what, population
- Develop processes across settings
- Determine education, resources

Palliative Care Program Elements*

Required element	Description
Interdisciplinary team	Have regular interdisciplinary team meetings.
Assessment and management of symptoms	Initial & ongoing, including physical and non-physical symptoms
Provider & care team education	Staff has sufficient & appropriate training relevant to roles on the team
Offer patient & family centered advanced care planning and goals of care	Have a policy/process to support patients in creating an advance directive if they do not have one
Care is accessible	May include access after hours, community-based resource support and services, care coordination, and continuity of care

*As defined by MN Hospice and Palliative Care Network to be listed in an online registry as offering a palliative care program.

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The Action Plan

Rural, Community Based Palliative Care Action Plan

Overall Goal: **Target Population:**

Objectives (think about SMART* criteria):

* SMART: specific, measurable, achievable, relevant and time bound objectives

	Process Steps	Responsible Person	Date/Timeline
Objective 1			
Objective 2			
Objective 3			

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Identifying People Appropriate for Palliative Care

- You would not be surprised if the patient died within year or two
- >1 or 2 admissions in several months
- Symptom complexity
- Decline in function, i.e., failure to thrive
- Advanced disease: met cancer, chronic home oxygen use; Nursing Home + falls

Identifying People Appropriate for Palliative Care

- Advanced illness + no healthcare directive/advance directive (HCD/AD)
- Admission to hospital from hospice
- Complex care requirements
- Limited social support in setting of serious illness

Third Step: Define Measures

Key Measurement Areas:

- Operational
- Clinical
  - Symptom management
  - Goals of care
  - Support to patient/caregiver
  - Transition management
- Satisfaction

Operational Measures

Operational

- Who are our patients?
- Who refers to our program?
- What happens after hour intervention?
- Costs and revenue

Clinical Measures: Symptom management

- Assessment on initial visit
- Plan for symptom reduction
- Reassessment for moderate-severe symptoms
- Changes in symptom scores over time

Clinical Measures: Goals of Care/Treatment Discussions

- Diagnosis, prognosis, treatment options reviewed
- Goals of care identified
- Plans to meet goals documented
- Preferred setting for care
- Advance care plan; shared decision making

Clinical Measures: Psychosocial, Spiritual Support

- Needs identified
- People important to patient
- Coping strategies and support
- Plan to meet needs with follow-up actions

Clinical Measures: Transitions and Anticipatory Guidance

- Define what should be communicated across care settings
- Patients understanding of prognosis
- Healthcare Directives,
  Shared Decision Making with. contact information
- Symptom management plans
- Community services
- Recommendations for next steps

Satisfaction Measures

- Patient and family
- Referring clinicians
- Health system
- Stakeholders
- Philanthropists

Palliative Care Programs Have Been Developed in:

- Hospitals, palliative care clinics, home programs, nursing homes
- Clinicians equipped with primary palliative care skills is essential for ongoing success

Examples of Palliative Care Programs

- Hospitals
- Palliative care clinics
- Palliative care home programs
- Nursing homes
- Community-centric programs

Palliative Care in Hospitals

- Review of patients at time of admission and daily for unmet palliative needs
- ICU family meetings
- Document discussion of prognosis and goals of care
- Bereavement

Clinic and Home Palliative Care

- Pain and symptom assessment and management
- Care planning
  - Advance directives, POLST (Physician Orders for Life Sustaining Treatment)
- Care management
- Linking to community resources
- Specialized palliative care education for home care staff

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Nursing Homes

- Pain and symptom assessment and management
- Advance care planning; identifying goals of care; POLST
- End of life care: care of the dying patient, comfort care orders, bereavement, staff support

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Community Focus Areas for Partnerships and Education

- Working with volunteers to meet practical and social needs of patients in your program
- Are Parish nurses or organizations that focus on working with aging citizens available? If so, these could be wonderful partners to identify patients and/or engage the community
- Collaboration with Alzheimer's or cancer initiatives
- Education about advance care planning

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What Does a Rural Palliative Care Program Look Like?

- Wide variation in structure and focus for the teams that have developed formal programs
- Process and system improvements are key component:
  - Process for supporting and documenting discussions of prognosis and goals of care
  - Shared order sets/care plans across settings
  - Professional and community education

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What does research show about collaboration?[1]

Essential elements	COOPERATION	COORDINATION	COLLABORATION
VISION AND RELATIONSHIPS	• Basis for cooperation is usually between individuals but may be mandated by a third party • Organizational missions and goals are not taken into account • Interaction is on an as needed basis, may last indefinitely	• Individual relationships are supported by the organizations they represent • Missions and goals of the individual organizations are reviewed for compatibility • Interaction is usually around one specific project or task of definable length	• Commitment of the organizations and their leaders is fully behind their representatives • Common, new mission and goals are created • One or more projects are undertaken for longer term results
STRUCTURE, RESPONSIBILITIES, & COMMUNICATION	• Relationships are informal; each organization functions separately • No joint planning is required • Information is conveyed as needed	• Organizations involved take on needed roles, but function relatively independently of each other • Some project-specific planning is required • Communication roles are established and definite channels are created for interaction	• New organizational structure and/or clearly defined and interrelated roles (a formal division of labor) are created • More comprehensive planning is required, i.e., developing joint strategies & measuring success in terms of impact on needs of those served • Clear information is a keystone of success; many 'levels' of communication are created
AUTHORITY AND ACCOUNTABILITY	• Authority rests solely with individual organizations • Leadership is unilateral and control is central • All authority and accountability rests with the individual organization which acts independently	• Authority rests with the individual organizations but there is coordination among participants • Some sharing of leadership and control • There is some shared risk, but most of the authority and accountability falls to the individual organizations	• Authority is determined by the collaboration to balance ownership by the individual organizations with expediency to accomplish purpose • Leadership is dispersed, and control is shared and mutual • Equal risk is shared by all organizations in the collaboration
RESOURCES AND REWARDS	• Resources (time, $$, etc.) are separate, serving individual organization's needs • Rewards, benefits are separate	• Resources are acknowledged and can be made available to others for a specific project • Rewards are mutually acknowledged	• Resources are pooled or jointly secured for a longer-term effort that is managed by the collaborative structure • Organizations share in the products; more is accomplished jointly than could have been individually

[1] Mattessich, Paul W. and Monsey, Barbara R. *Collaboration: What Makes It Work.* St. Paul, Minnesota: Amherst H. Wilder Foundation, 1992.

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Variables In Program Structure

Methods of service delivery	Interdisciplinary team	Patient focus	Coordinating staff
Home visits Clinic appointments Nursing home visits Inpatient consultation Telephonic case management Volunteer support visits/services	All teams included physician, social work, nursing Other disciplines vary: •Rehabilitation services •Volunteers •Nurse practitioner •Chaplain •Pharmacy •Advance practice nurse in psychiatry	Hospice eligible but refused Infusion therapy Home care with complex illness Inpatient consult when requested Physician referred with complex illness Nursing home residents – triggered by minimal data set (MDS) criteria	Nurse practitioner Registered nurse Social worker Certified nurse Specialist Advance practice nurse

Examples of Palliative Care Models in Rural Communities

- Build a team around the patient, primary physician/ APP(Advance Practice Provider), and family.
- Nurse Practitioners offer consults, pulling in other member of the care team.
- Triaging patient needs to identify frequency of visits and team member. May also include connections to social services supports or volunteer visitors.
- In some areas, telemedicine plays a role.

Key Issues in Palliative Care

Key Issues in Palliative Care: Language Matters

- When we try to sell dying, we turn away the majority of patients who need our help
- For patients: improving concerns as they perceive them
- For health care agencies: quality, less resource use
- For physicians, APPs: time, help with pain and communication, ACP, POLST

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Marketing

- A key part of program development is to create access to quality care for patients with serious illness and their families
- Explain the who-what-why-where
- Important to use language that talks about benefits to patients and families--stories work great
- Target information to what audience cares about: different messages to different audiences

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Key Issues in Palliative Care: Education

- For your team
  - Options: self-study, on line courses, conferences, ELNEC (End of Life Nursing Education Consortium), Fast Facts, APRN (Advance Practice Registered Nurse) Externship program
- For your community
- For your colleagues

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Key Issues in Palliative Care: Finances

- MD/APP Provider revenue (like any consult or follow up in any setting)
- Cost avoidance: less resource use with alignment of care plan with patient goals
- Possible increased LOS in hospice
- Potential for alignment with Chronic Care Management billing codes

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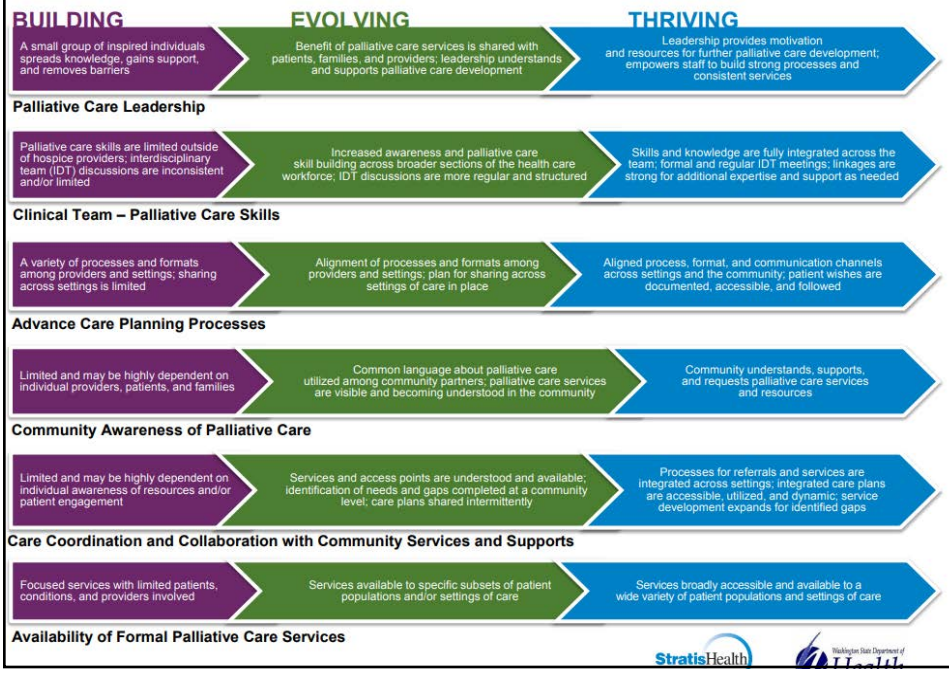
Rural Palliative Care: Strategies for Sustainability

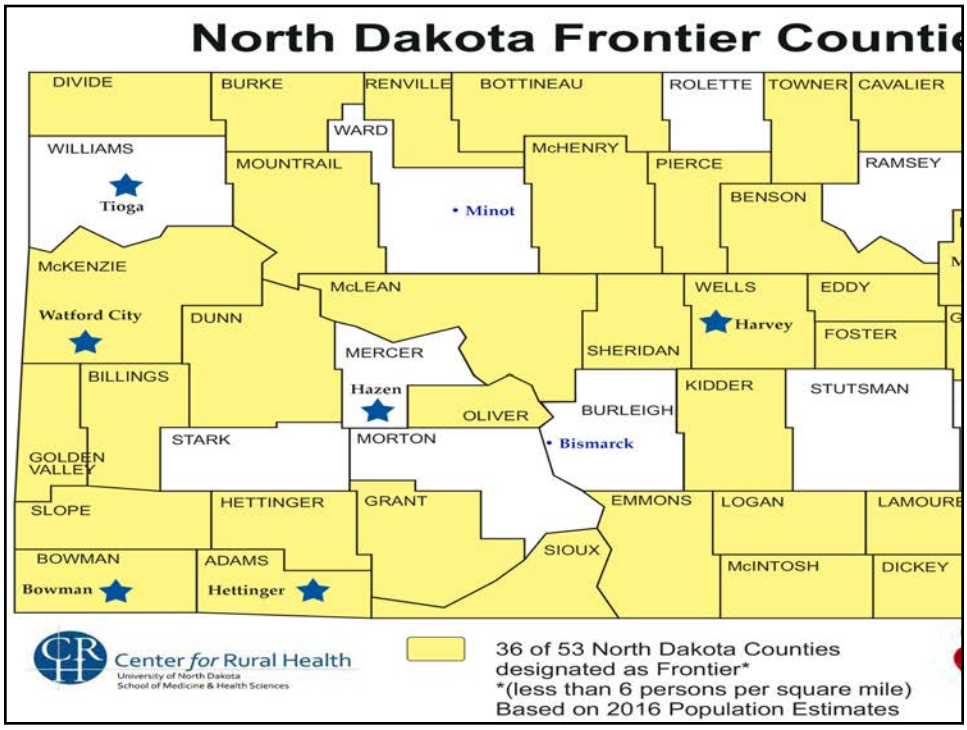
Billing/FFS Reimbursement	Grants & Philanthropy	Value-Based Contracting	Emerging Opportunities
What: Direct billing for specific services **How:** Provder Visits • Physician • APRN/PA • MSW (in some situations) Care Coordination Codes • Chronic Care Management (CCM) • Transition Care Management (TCM) Advanced Care Planning (ACP) Alignment with home care services under Medicare reimbursement.	**What:** • Federal, state, local grant opportunities • Donations or local foundation funds (i.e. auxiliary) **How:** • Dedicate use of local foundation funds to off-set costs • Bequests or larger gifts – targeted to support services in a variety of ways • Often one-time funds to support development	**What:** • Accountable Care Organizations (ACOs) • Bundled Payments • Other population based or risk-sharing arrangements **How:** Focus on understanding patient goals and active care planning can help: • Reduce potentially avoidable utilization • Decrease use of high cost treatments and medications as aligned with patient goals • Generate savings, meet quality or utilization based incentive targets	**What:** Medicaid programs, Medicare Advantage plans, and/or other payers develop palliative care reimbursement or benefit options (varies by state and market) **How:** Advocate for development of palliative care reimbursement or benefit programs, ideally with implementation aligned across payers in your state/region.

Underlying Value

- *"Because it is the right thing to do"*
- Improved quality of care and quality of life for patients with serious illness and/or complex needs
- Patient and family/caregiver satisfaction
- Provider and staff satisfaction and resiliency
- Palliative care team can support difficult conversations and management of seriously ill patients, reducing provider stress and freeing up time to see other patients

Community Team Development





Education Resources for Palliative Care

- GetPalliativeCare.Org
- Center to Adavance Palliative Care (CAPC)
- PCNOW Fast Facts (Palliative Care Network of Wisconsin)
- HPNA ELearning (Hospice and Palliative Nurses Association)
- CSU Institute for Palliative Care
- MJHS Institute for Innovation in Palliative Care

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Advance Care Planning Resources

- National Healthcare Decisions Day
- The Conversation Project
- Respecting Choices
- POLST Care Continuum Toolkit
- Serious Illness Conversation Guide

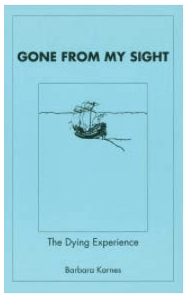
North Dakota Resources

- North Dakota Rural Community-Based Palliative Care Project
- North Dakota Palliative Care Taskforce
- Honoring Choices North Dakota
- North Dakota POLST
- Nancy Joyner Consulting,P.C.

Patient Education Resources

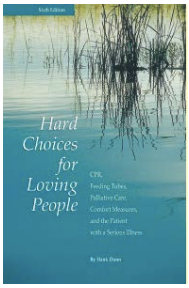
Ice Breakers

- Go Wish Game
- Hello, Common Practice Game



Hard Choices for Loving People Booklet

Gone From My Sight Booklet Booklet



Questions???

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https://ruralhealth.und.edu/projects/community-palliative-care


Start where you are,
use what you have,
do what you can.
- Arthur Ashe
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