# Rural Community-based Palliative Care
*Improving health and reducing disparities in access and services*



## *A toolkit for designing high-value, customized programs*

Strengthening organizational capacity, redesigning care delivery, and building community capacity are at the heart of Stratis Health's rural palliative care approach.

This toolkit is a starting point for designing high-value custom rural, community-based palliative care programs that ease challenges for individuals, families, caregivers, clinicians, and communities dealing with serious illness.

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# INTRODUCTION

For more than a decade, Stratis Health has pioneered processes for establishing and supporting palliative care services in smaller, rural communities. Recognizing that existing best practices are designed for larger hospitals or health systems serving urban areas, Stratis Health has addressed this gap by supporting more than 45 rural communities across the country in building capacity to offer palliative care services.

Rural communities can provide palliative care services effectively, yet models for service delivery vary widely. Community-based teams are a core component of developing palliative care capacity in rural areas by building on existing strengths and resources.

Based on years of experience in working with rural communities to develop services, this toolkit contains a framework to assist communities with program development by identifying key components to build a foundation, develop processes, and launch service implementation.

The framework supports community teams in identifying community-specific goals and assets and provides guidance and links to a variety of resources for implementation of a plan for program development that is tailored to meet community needs.

## Stratis Health's Impact

Stratis Health has supported more than 45 rural communities in six states in developing rural community-based palliative care services:

- Helped community teams improve levels of experience or expertise in a variety of core palliative care processes.

- Decreased unnecessary health care utilization (emergency department visits and hospital stays).

- Achieved patient-reported improvements in 7 of 9 symptoms assessed, with notable decreases in pain and depression.

- Earned high patient satisfaction ratings by ensuring support that honors stated goals.

*"Rural communities have significant need for palliative care and are uniquely positioned to meet the challenges through collaborative, community-based efforts to address disparities in access and services."*

*- Jennifer P. Lundblad, PhD, MBA,*
*Stratis Health President & CEO*

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# WHY PALLIATIVE CARE IS VITAL IN RURAL COMMUNITIES

Palliative care principles and practices can support seriously ill patients, their families, and caregivers across all settings of care. Rural communities have unique opportunities and challenges in providing holistic serious illness care that enhances the quality of life for patients and their families or caregivers. The following key concepts and resources can assist with gaining a common understanding of palliative care and how to begin a rural community-based program.

**Palliative care is a newer field for many health care providers.**

This approach to managing serious and advanced illness centers on relieving suffering and improving quality of life for patients and their families or caregivers. Palliative care teams help patients and their families or caregivers understand treatment options and facilitate effective communication among health care professionals, patients, family members and caregivers—bringing together the support systems that patients need to determine how to plan for the best quality of life and care. Palliative care differs from hospice in that it is appropriate at any point in a serious illness and can be provided at the same time as curative treatment.

**People in rural communities have less access to palliative care services, but potentially greater need.**

To date, most palliative care programs have been developed primarily in large hospitals in urban settings. Delivery models for rural community-based palliative lags even though rural populations are disproportionately ill, disabled, poor, and older. Rural adults also are more likely than their urban counterparts to have a range of chronic conditions.
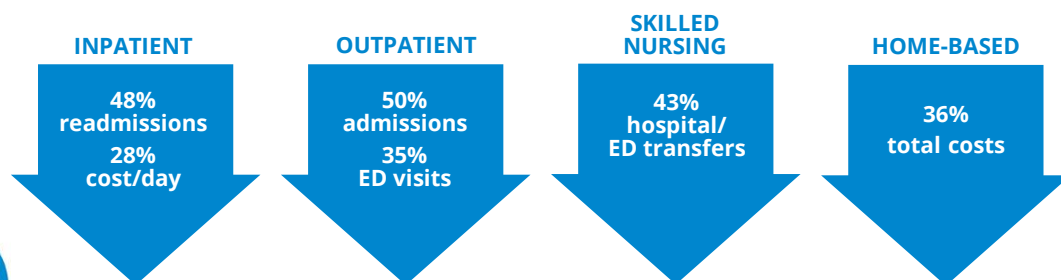
**Palliative care is growing in importance in care delivery.**

As our population ages, as awareness of the benefits of palliative care grows, and as pressure to improve value in health care continues, palliative care will move to a place of greater prominence in the health care delivery system.

## To learn more:

- Introduction to Building a Community Palliative Care Program: An overview of the basics of palliative care and creating a program. (39-minute video), slides (46-page PDF)

- Center to Advance Palliative Care: About Palliative Care overview including links to patient stories.

- Palliative Care: The Relief you Need when you have a Serious Illness: Guide for patients and their families. from the National Institute of Nursing Research. (16-page PDF)

## PALLIATIVE CARE REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS
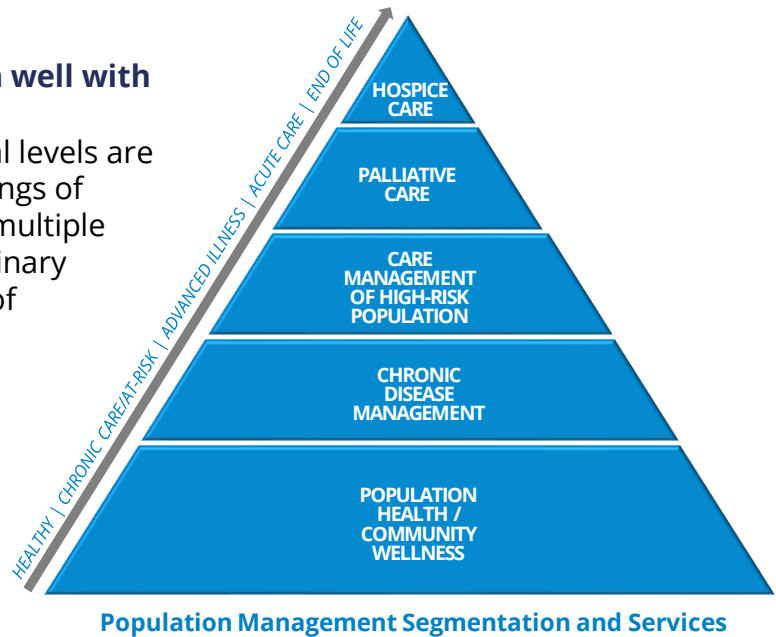
**INPATIENT**
48% readmissions
28% cost/day

**OUTPATIENT**
50% admissions
35% ED visits

**SKILLED NURSING**
43% hospital/ ED transfers

**HOME-BASED**
36% total costs

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*Source: Center to Advance Palliative Care, 2023*

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**Palliative care programs and services align well with other efforts to redesign care delivery.**
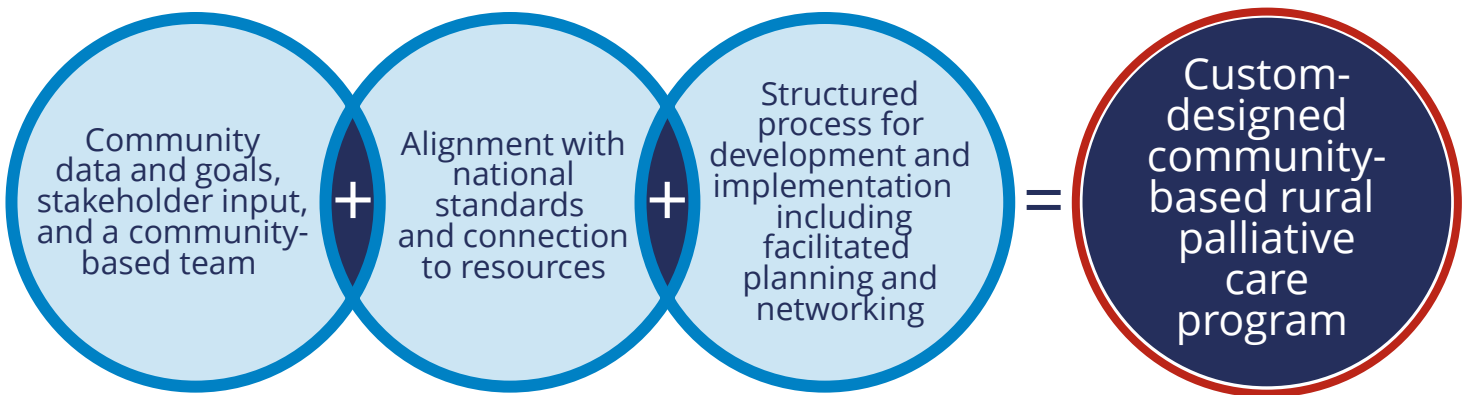
Health reform efforts at the state and national levels are calling for increased coordination across settings of care and increased focus on individuals with multiple chronic illnesses. Development of interdisciplinary palliative care services can be a cornerstone of better addressing the needs of patients with serious illness and high health care costs and can be a critical strategy to support population management under value-based care contracts.



HOSPICE CARE

PALLIATIVE CARE

CARE MANAGEMENT OF HIGH-RISK POPULATION

CHRONIC DISEASE MANAGEMENT

POPULATION HEALTH / COMMUNITY WELLNESS

HEALTHY | CHRONIC CARE/AT-RISK | ADVANCED ILLNESS | ACUTE CARE | END OF LIFE

**Population Management Segmentation and Services**

**Rural communities are uniquely positioned to meet the challenges of providing palliative care through collaborative efforts.**

Stratis Health has developed a community-capacity based formula for supporting rural communities to develop their abilities to improve quality of life for those facing serious illness.

## The Stratis Health Formula for Program Development



Community data and goals, stakeholder input, and a community-based team **+** Alignment with national standards and connection to resources **+** Structured process for development and implementation including facilitated planning and networking **=** Custom-designed community-based rural palliative care program
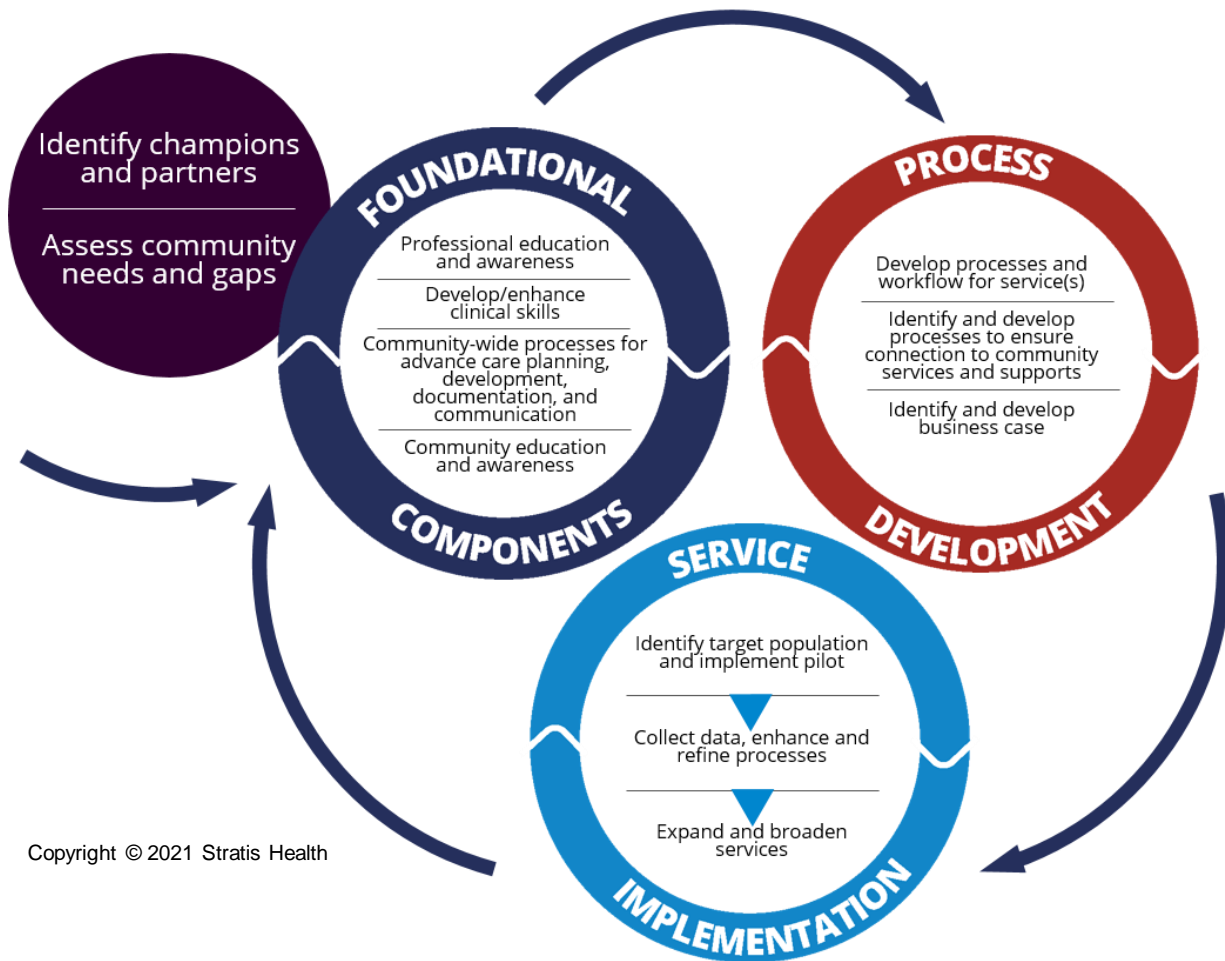
Community capacity development is strengths-based, pragmatic, and inclusive. Change primarily comes about through enhancing existing capacities rather than creating something brand new. The approach requires collaborative leadership, broad participation, and the willingness of a community to learn over time. Stratis Health has found that community capacity development is well suited to rural communities because they often have a keen awareness of their strengths and opportunities and a deep understanding of their culture, which can combine to identify and implement tailored solutions that best fit their unique situation.

The combination of this strengths-based approach paired with a structured process for development that includes facilitated planning, alignment to national standards, and connections to resources and networking opportunities results in development of rural palliative care programs that are custom designed to match a communities needs and resources.

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# Rural Community-based Palliative Care Service Development Framework

Stratis Health has identified a framework of key interdependent elements to guide in supporting rural community teams in development of palliative care capacity and services. This toolkit identifies resources to support implementation of each of the key framework components.



Identify champions and partners

Assess community needs and gaps

**FOUNDATIONAL**

Professional education and awareness

Develop/enhance clinical skills

Community-wide processes for advance care planning, development, documentation, and communication

Community education and awareness

**COMPONENTS**

**PROCESS**

Develop processes and workflow for service(s)

Identify and develop processes to ensure connection to community services and supports

Identify and develop business case

**DEVELOPMENT**

**SERVICE**

Identify target population and implement pilot

Collect data, enhance and refine processes

Expand and broaden services

**IMPLEMENTATION**

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The framework begins with identification of community champions and partners who work together to assess community needs and gaps as well as identify resources and assets. Most community teams start with a focus on building foundational components of palliative care such as professional education and awareness, development of clinical skills, advance care planning processes, and outreach into the community. Work on these foundational efforts are often ongoing throughout a community's journey towards service development and implementation.

Prior to implementation of services, next steps include process development related to patient identification and workflow, documentation, connection to community services, and consideration of the business case and any billing/reimbursement opportunities. Community teams are encouraged to use a quality improvement approach for implementation of palliative care services by identifying a target population and using small tests of change to develop and refine workflows with a limited number of patients, before expanding and broadening as processes are established.

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# Getting Started: Building a team and assessing needs and resources

**Identify champions and partners**
_____
**Assess community needs and gaps**

Identifying champions, partners and stakeholders with an interest in improving serious illness care to form a community team is a key first step in a community-capacity based approach. Community teams can then work together to identify needs, set goals, and assess resources and gaps to identify next steps in capacity and service development.

The following resources from Stratis Health assist with developing a team and assessing community assets and gaps.

## Identify champions and partners

- **Assemble the team:** This resource includes considerations for identifying a community team leader and team members. (1-page PDF)
- **Invite the team:** Template message to invite members to your community team. (2-page Word template)
- **Initial community team meeting discussion guide**: Sample agenda to support team leaders in engaging community partners. (2-page PDF)
- **Mission, Vision, Goals:** Establishing a shared vision, mission, and goals is ensures that everyone on the team understands the integrity commitment of the rural community-based palliative care program. These examples may he a helpful starting place. (1-page PDF)
- **Community Team Development Continuum:** Development of palliative care services in rural communities is a journey. This resource provides a portrait of the progression of the team development components as community work towards implementation. (Diagram in Appendix, page 11)

## Assess community needs and gaps

- **Asset and gap analysis:** Key questions to assist community teams in identifying resources, needs, and opportunities related to palliative care service development. (2-page PDF)
- **Case Studies:** These case studies can be used for discussion with community teams to help identify existing resources and gaps in service availability. (2-page PDF)
- **Action Plan Template and Examples:** Template that can be used for development of a community action plan and examples of an initial community team action plan. (1-page Word template), Action plan examples. (3-page PDF)

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# Foundational Tools and Resources

Taking time to understand and establish foundational components helps ensure the successful implementation of a rural community-based palliative care program. A focus on foundational components often occurs concurrently with process development and service implementation and are an ongoing part of palliative care service implementation.

## Professional education and awareness

- **Clinical Practice Guidelines for Quality Palliative Care, 4th Edition:** These guidelines expand on the eight domains of palliative care and include examples, tools, and resources. National Coalition for Hospice and Palliative Care (2018)
- **Introduction to Palliative Care:** A brief overview of palliative care for healthcare professionals (15 -minute video), slides (5-page PDF)  Stratis Health (2020)
- **Professional Education and Certifications**: This resource list provides a summary of the wide variety of professional education and certification opportunities available across different disciplines related to palliative care. (2-page PDF) Stratis Health (2021)
- **Achieving Health Equity**: This toolkit provides curated tools and resources to improve the quality of care provided to traditionally oppressed or excluded patients and move the needle on equity for all people living with serious illness. Center to Advance Palliative Care (2022)
- **Ethnic-specific geriatric care in the United States:** Educational modules from the Stanford School of Medicine focus on the health of 13 ethnicities in the US. Stanford School of Medicine.

## Develop/enhance clinical skills

- **Center to Advance Palliative Care (CAPC):** CAPC offers tools, resources, and clinical training to assist in developing, strengthening, and expanding palliative care programs. *(Please note that some tools are for members only).* CAPC offers special membership rates for Critical Access Hospitals.
- **Palliative Care Fast Facts and Concepts:** Fast Facts provide concise, practical, peer-reviewed, evidence-based summaries on key palliative care topics important to clinicians caring for patients facing serious illness. Palliative Care Network of Wisconsin (PC Now).
- **Palliative care for adults:** This evidence-based clinical practice guideline assists clinicians with discussions, interventions, and utilization of palliative and hospice care for adult patients. Institute for Clinical Systems Improvement (ICSI) (2020)
- **Edmonton Symptom Assessment System (ESAS-r) Training:** Palliative care expert Lyn Ceronsky DNP, GNP, FPCN, provides an overview of clinical assessment using ESAS-r. (46-minute video) slides (20-page PDF) Stratis Health (2018)
- **VITAL talk:** Includes a variety of short videos and one-page quick guides to support effective communication with patients living with serious illness
- **Project ECHO:** Project ECHO is a nationally recognized model for reducing health disparities in underserved areas through a technology-supported hub-and-spoke approach for knowledge sharing and peer-to-peer engagement. This link allows users to filter for active ECHO program by area of focus (select palliative care).

# Foundational Tools and Resources cont.



Taking time to understand and establish foundational components helps ensure the successful implementation of a rural community-based palliative care program. A focus on foundational components often occurs concurrently with process development and service implementation and are an ongoing part of palliative care service implementation.

## Community-wide processes for advance care planning, development, documentation, and communication

- **The Conversation Project:**  A public engagement initiative with a goal that is both simple and transformative: to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. Includes information, tools, and resources for community outreach and health care professionals. Institute for Healthcare Improvement
- **Advance Care Planning Resources:**  A variety of tools, trainings, and resources are available to support development of advance care plans.
    - Five Wishes
    - Light the Legacy/Honoring Choices
    - Respecting Choices
- **National POLST**: Nonprofit organization that organizes the effort to standardize the POLST process, form and education throughout the U.S., since POLST varies from state to state.

## Community education and awareness

- **Promoting your program:** This resource provides tips and a sample news release template for promoting local programs. (2-page PDF) Stratis Health.
- **Template PowerPoint presentation:** Sample presentation that can be adapted and tailored for community education and outreach. (17-page PPT template) Stratis Health
- **Patient and caregiver education:** Several resources are available for patient, caregiver, or public education about palliative care.
    - **Compassionate care at any stage of an illness:** This patient site provides a wealth of information on hospice, palliative care, what to expect from a palliative care team, and patient stories. American Academy of Hospice and Palliative Medicine.
    - **End-of-life: Helping with Comfort and Care:** This booklet, available to order or download, helps people make sound health care decisions at the end of life. National Institute of Aging.
    - **GetPalliativeCare.org:** This website provides comprehensive palliative care information for people coping with serious, complex illness. Center to Advance Palliative Care (CAPC).
    - **What Are Palliative Care and Hospice Care?** This webpage provides and overview explains the difference between the two care options. National Institute on Aging.
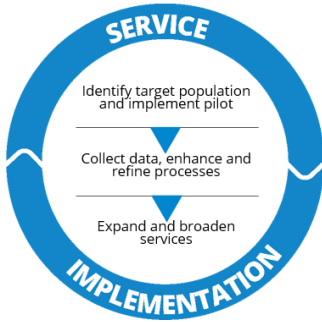
# Process Development Tools and Resources

Addressing the holistic needs of the patient through a serious illness takes a skilled interdisciplinary team. Providing symptom management, continuity with support and care, and facilitating communication between providers while advocating for the patient's and family's wishes are key skills for the interdisciplinary team. These resources and tools support development of processes, workflow, and a business case to start providing palliative care services.

- **Variables in Program Structure:** Flexibility in structure and process is a key component to development of a sustainable palliative care program in rural communities. A sample how a variety of rural programs have structured key elements can be found in the diagram in Appendix (page 12).
- **Center to Advance Palliative Care (CAPC):** Toolkits for Palliative Care Programs includes resources for developing programs in a variety of settings. Website has free and for members only sections. CAPC offers special membership rates for Critical Access Hospitals.
- **Sample Referral Criteria:**
    - **Three Methods to Identify Patients Appropriate for Palliative Care:** This scoring tool outlines three methods for care teams to evaluate when palliative care is appropriate. (2-page PDF) **Palliative Care Referral Criteria:** This scoring tool includes general, neurological, and cancer criteria for evaluation of a patient's need for palliative care. (2-page PDF)
- **Elements of Consultation:** Case example highlighting key elements of a palliative care consultation. (1-page PDF). Stratis Health.
- **Edmonton Symptom Assessment Tool** – Revised (ESAS-R): Quantitative symptom assessment tool that has regularly been utilized by rural palliative care teams. Summary article, downloadable tool (2-page PDF), instruction manual (39-page PDF)
- **Assessment tools for palliative care:** Technical brief offers an overview of assessment tools for application in clinical care. (145-page PDF) Agency for Healthcare Research and Quality (2017)
- **Spiritual assessment:** Physicians can support patients by practicing empathetic listening, incorporating faith traditions into treatment plans, and encouraging patients to turn to spiritual traditions and communities for support. American Family Physician (2012)
- **Sustainability Strategies For Rural Community-based Palliative Care:** A summary of field-tested approaches and supporting resources to assist rural community-based palliative care programs to identify financial strategies and build a business case including information on coding and billing, grants and philanthropy, and alignment with value-based reimbursement. (9-page PDF) Stratis Health (2023)
- **Telehealth and Palliative Care:** Telehealth is one option to consider when developing workflow and processes. This toolkit covers all aspects of palliative care telehealth delivery, including selecting the technology platform, setting up a hotline, billing for services, and conducting a visit. CAPC (membership required for access of some tools)
- **Weaving Palliative Care into Primary Care: A Guide for Community Health Centers**: Introduces primary palliative care and a detailed description of the steps required to plan, build, and integrate a primary palliative care program into a clinic setting. California Health Care Foundation (2015)

# Service Implementation Tools and Resources



Stratis Health encourages using a quality improvement (QI) approach to launching service implementation. Use the information obtained from completing your community's asset and gap analysis to identify the target population for a pilot program and start testing the workflows and processes that have been developed.

Common target populations for pilot programs in the Stratis Health initiatives have been:
- Physician or staff referred with complex care needs
- Hospice eligible, but patient declined hospice services
- Infusion therapy patients or those with specific diagnosis such as congestive heart failure
- Requests for inpatient consults for goals of care conversations and symptom management

As the pilot program is refined, expand and broaden services by selecting additional patient populations or settings to provide palliative care services in your community.

- **QI Basics:** Brief training modules and tools designed to equip professionals with the knowledge and tools to start quality improvement projects at their facilities. Stratis Health
- **Evaluation measures:** Sample evaluation metrics for rural community-based palliative programs to help measure and manage results. (1-page PDF) Stratis Health
- **Data collection tools:** Excel-based data collection tool and supporting resources to support patient level data collection for program management and quality measurement. Available upon request from Stratis Health. Contact info@stratishealth.org
- **Palliative Care Quality Collaborative**: Unified palliative care registry, launched in 2021, Offers three levels of participation.
    - Basic: Free - provide basic information about your program to be included in the Get Palliative Care provider directory.
    - Advanced: Free - programs submit data about their program reflecting the previous year. Provides actionable comparison data that programs can use to secure, expand and retain resources for delivery of high-quality palliative care
    - Premium: Cost varies depending on size and type of program - collection of standardized data that include clinical outcomes for each patient. Members can generate reports to monitor their program and to benchmark outcomes to peer groups
- **Rural Program Examples**:
    - Rural Community Based Palliative Care Project Site Visit Reports. NORC Walsh Center for Rural Health
        - North Dakota (5-page PDF)
        - Washington (5-page PDF)
    - Models and Innovations. Rural Health Information Hub
        - HopeWest (CO)
        - Project ENABLE (Educate, Nurture, Advise, Before Life Ends)

## CONTENTS
- Stratis Health Published Work and partner sites related to rural palliative care development. (page 10)
- Rural Palliative Care: Community Team Development diagram (page 11)
- Variables in Program Structure table (page 12)

**Additional information: Stratis Health Published Work**
- **Stratis Health Project Brief - Rural Community-based Palliative Care, 2017-2020:** Highlights of a three-year project to expand and support development of rural community-based palliative care teams and services in Minnesota, North Dakota, Washington, and Wisconsin. (3-page PDF) *(March 2021)*
    - Rural Community-based Palliative Care: 2017-2020, Final Report: The NORC Walsh Center for Rural Health Analysis performed an external evaluation of the program outcomes, both quantitative results (i.e., reduction in in health care utilization, improved patient-reported outcomes, and increased care team knowledge and skills) and qualitative results and experiences, including case studies about the experience of rural communities in participating states. (62-page PDF) *(February 2021)*
    - Stratis Health Project ECHO Summary Report: Overview of the implementation of a nine-month Project ECHO focused on palliative care clinical skill development with 11 rural Minnesota community teams. Project ECHO is a nationally-recognized model for reducing health disparities in underserved areas through a technology-supported hub-and-spoke approach for knowledge sharing and peer-to-peer engagement. (6-page PDF) *(March 2021)*
- **Rural Quality Care: Meeting Patients Where They Are:** During this recorded Coalition to Transform Advanced Care presentation, experts from Stratis Health discuss the challenges of providing quality hospice and palliative care in a rural setting and share strategies to guide groups working to serve these communities. (53-minute video), slides (19-page PDF) *(April 2019)*
- **Stratis Health Rural Palliative Care Impact Report:** Summarizes rural palliative care initiatives implemented from 2008 – 2014. (28-page PDF) *(July 2016).*
- **Palliative Care in Rural Minnesota: Findings from Stratis Health's Minnesota Rural Palliative Care Initiative:** (Page 40-43 PDF) *Minnesota Medicine, January/February 2016*
- **Quality Measures for Community-based, Rural Palliative Care Programs in Minnesota: A Pilot Study:** A standard set of quality measures were field tested and evaluated for use in rural community-based palliative care programs. *Journal of Palliative Medicine, June 2015, article abstract.*
- **Rural Palliative Care Initiative: Building Palliative Care Capacity in Rural Minnesota** *Journal of Palliative Medicine, February 2013, article abstract*
- **Palliative Care — More Than Just Hospice, with Karla Weng and Pat Justis:** Podcast, Rural Health Information Hub, June 2022
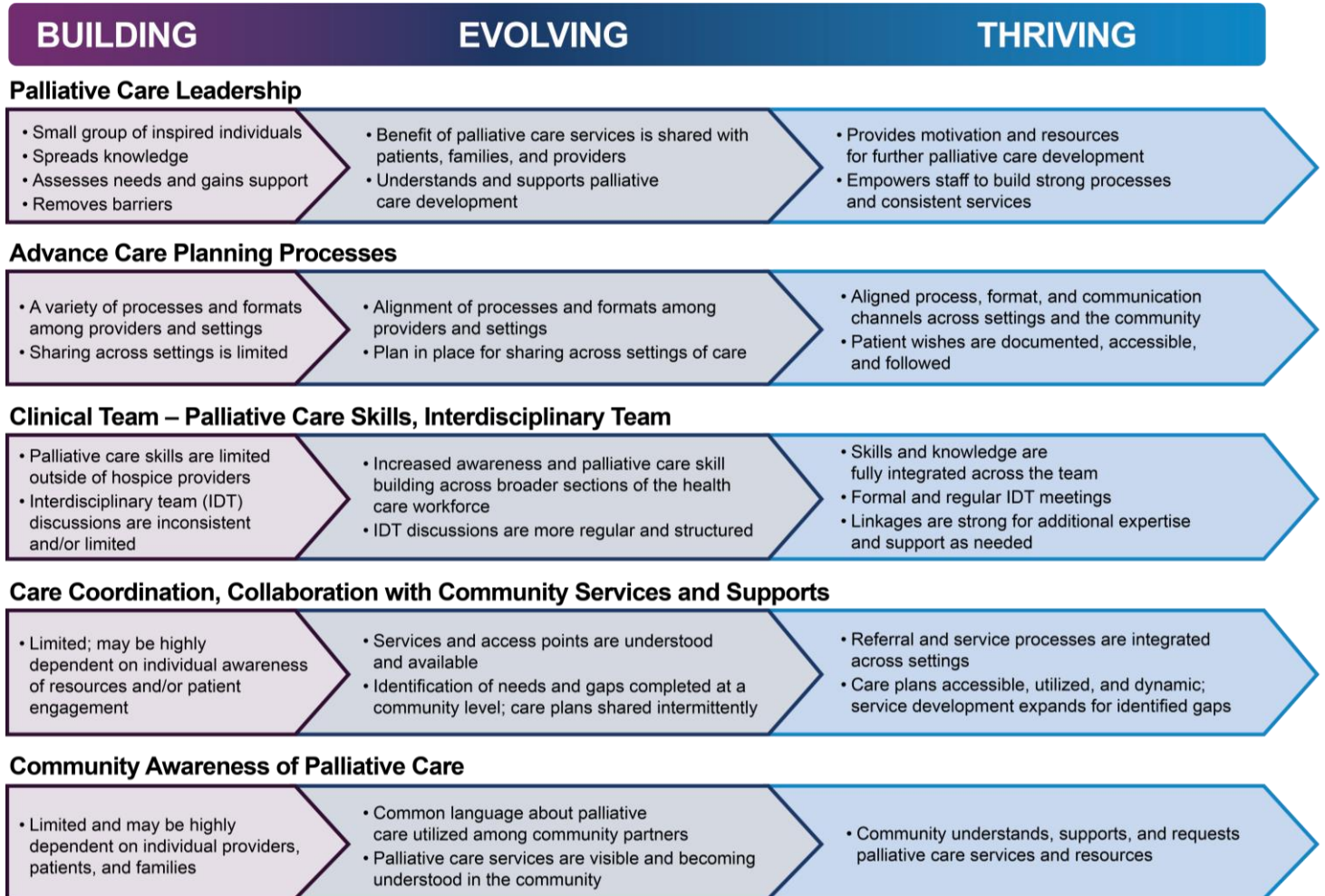
**Partner site**
**Washington Rural Palliative Care Initiative**

# Rural Palliative Care: Community Team Development

| BUILDING | EVOLVING | THRIVING |
|---|---|---|

**Palliative Care Leadership**

| BUILDING | EVOLVING | THRIVING |
|---|---|---|
| • Small group of inspired individuals<br>• Spreads knowledge<br>• Assesses needs and gains support<br>• Removes barriers | • Benefit of palliative care services is shared with patients, families, and providers<br>• Understands and supports palliative care development | • Provides motivation and resources for further palliative care development<br>• Empowers staff to build strong processes and consistent services |

**Advance Care Planning Processes**

| BUILDING | EVOLVING | THRIVING |
|---|---|---|
| • A variety of processes and formats among providers and settings<br>• Sharing across settings is limited | • Alignment of processes and formats among providers and settings<br>• Plan in place for sharing across settings of care | • Aligned process, format, and communication channels across settings and the community<br>• Patient wishes are documented, accessible, and followed |

**Clinical Team – Palliative Care Skills, Interdisciplinary Team**

| BUILDING | EVOLVING | THRIVING |
|---|---|---|
| • Palliative care skills are limited outside of hospice providers<br>• Interdisciplinary team (IDT) discussions are inconsistent and/or limited | • Increased awareness and palliative care skill building across broader sections of the health care workforce<br>• IDT discussions are more regular and structured | • Skills and knowledge are fully integrated across the team<br>• Formal and regular IDT meetings<br>• Linkages are strong for additional expertise and support as needed |

**Care Coordination, Collaboration with Community Services and Supports**

| BUILDING | EVOLVING | THRIVING |
|---|---|---|
| • Limited; may be highly dependent on individual awareness of resources and/or patient engagement | • Services and access points are understood and available<br>• Identification of needs and gaps completed at a community level; care plans shared intermittently | • Referral and service processes are integrated across settings<br>• Care plans accessible, utilized, and dynamic; service development expands for identified gaps |

**Community Awareness of Palliative Care**

| BUILDING | EVOLVING | THRIVING |
|---|---|---|
| • Limited and may be highly dependent on individual providers, patients, and families | • Common language about palliative care utilized among community partners<br>• Palliative care services are visible and becoming understood in the community | • Community understands, supports, and requests palliative care services and resources |

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Access this resource as a full-page handout:
https://stratishealth.org/wp-content/uploads/2020/07/pc-team-development-continuum-dia.pdf

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# Variables in Rural Palliative Care Program Structure

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

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## About Stratis Health

- The Stratis Health team is comprised of multi-faceted experts who specialize in helping rural communities build and sustain successful palliative care programs.

- Our agile staff delivers data-driven insights, evidence-based interventions, and leading-edge improvement methodologies that inspire organizations and communities to discover and implement solutions to persistent challenges associated with treating advanced and complex illness.

- We have deep expertise in working with vulnerable and underserved populations including rural, minority, and low-income populations.

- Stratis Health is uniquely qualified to increase access to high-quality, patient-centered, coordinated care and support.

Please contact Stratis Health for more information about making palliative care available in rural communities to improve health and reduce disparities in access and services.

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