

# Nebraska Palliative Care and Quality of Life Advisory Council

## PROGRESS REPORT AND RECOMMENDATIONS

Released 2022

Positions taken by the Nebraska Palliative Care and Quality of Life Advisory Council are not endorsed by the Nebraska Department of Health and Human Services. The Nebraska Palliative Care and Quality of Life Council is an independent council.

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# Palliative Care: Lou's Journey

Our journey with Lou has been everything but normal. On the day we went to learn his gender, we were told not to expect our little boy to survive. That began a journey of numerous appointments, tests, and sleepless nights, until we were referred to the “Hand in Hand Palliative Care” team at Children’s Medical Center in February 2020. The team asked us to define what our goals were for our little guy and what our definition of quality of life was. All we knew was that we wanted Lou to live a life knowing that he is so very loved, have every opportunity to be happy, and to be free from pain.

Our little fighter arrived in April 2020. Those first few days felt like weeks – meeting with doctors and nurses, learning about tests and procedures, and making plans for what was to come. The COVID-19 pandemic made it that much harder to form relationships with Lou’s care team, and left us feeling alone when only one of us could be with Lou in his hospital room due to visitor restrictions. But the Hand in Hand Palliative Care team helped fill the void. Through our ten months at Children’s, two months in a long-term



care facility, the transition home to our farm, and ongoing care, they have been by our sides. The caseworker has been a lifeline in coordinating Lou's many specialists and appointments, and ensuring that the right person answers our questions. The palliative care doctors attended to his medical needs and helped navigate any challenging interactions with other staff. As we prepared to go home, the social worker helped us find contacts, fill out applications, and get the support we needed so we could focus on loving and caring for our son. Healing touch, musical therapy, and other specialists have been essential in managing Lou's symptoms and enhancing his quality of life. And the palliative care team has been attentive to our needs – checking in on how we are doing and helping us find moments for our own self-care so that we can be present for our son.

Hand in Hand is a wonderful way to describe what the palliative care team does for its patients and their families. We do our best to keep Lou home and healthy, but he continues to be a stubborn medical mystery. We have grieved for “normal” first parent experiences, and it is all too easy to get stuck on the “didn't haves.” But if Lou wasn't medically complex, we would not have met the members of the palliative care team that helped us create new first parent experiences, and continue to ensure that our family has the resources we need to be together and give Lou the best life possible.



***Grant and Lacey Friesen  
Henderson, Nebraska  
(parents; son Lou, pictured)***

# Palliative Care: Marcia's Experience

I was diagnosed with Stage II-C colon cancer in June 2012, and then diagnosed with Stage III parotid gland cancer in November of 2020. My treatment regimens included surgery, chemotherapy, and 30 radiation treatments – the last of which occurred during the height of the COVID-19 pandemic in Nebraska. By the grace of God, I am still here, having received wonderful physical care. But as a career-long hospice and palliative care-certified RN, a bereaved family member who lost my beloved brother to an excruciating cancer battle in 2014, and a survivor myself, I feel very strongly that there must be greater access to palliative care across Nebraska. In addition to helping manage the physical symptoms of serious illness, palliative care can transform the experience by attending to the complete needs of the patient AND their family. By creating a care plan, ensuring that treatments are matched to goals, and supporting care coordination and communication, palliative care teams can significantly reduce patient and family suffering – often avoiding unnecessary emergency department visits and hospitalizations along the way. Access to this kind of care would have transformed my brother's experience; having a radiation oncologist who *did* have palliative care training was a saving grace for me and my husband when we were otherwise physically and socially isolated. My greatest hope is that, as part of the Nebraska Palliative Care and Quality of Life Advisory Council, I can use my personal and professional experiences to ensure that other Nebraskans will have access to this essential care moving forward.



***Marcia Cederdahl, RN, BS, CHPN  
Lincoln, Nebraska  
(nurse, cancer survivor, family member;  
pictured with husband, Ray)***

# Executive Summary

Palliative care is specialized medical care focused on relieving the symptoms and stress of a serious illness. It is appropriate at any age and at any stage, and can be delivered along with curative treatment. The goal is to improve quality of life.

The Nebraska Palliative Care and Quality of Life Advisory Council (Council) was established in 2017 to:

- Support public education on palliative care, and
- Make recommendations to state officials on ways to expand palliative care access to all Nebraskans living with serious illness.

This report provides an overview of the current palliative care landscape in Nebraska, a recap of the Council's activities in its first term, and recommendations for moving forward.

The Nebraska Palliative Care and Quality of Life Advisory Council would like to thank the following staff from the Nebraska Department of Health and Human Services: Shirley Pickens-White, Christine Esch, Andrea Wenke, Becky Wisell, Tina Goodwin, and Rebecca Martinez, who have provided invaluable support in this work.

Finally, the Council would like to dedicate this report to Senator Mark Kolterman and his late wife, Suzanne, for their leadership in ensuring that all Nebraskans living with serious illness have the best quality of life possible.

# Introduction

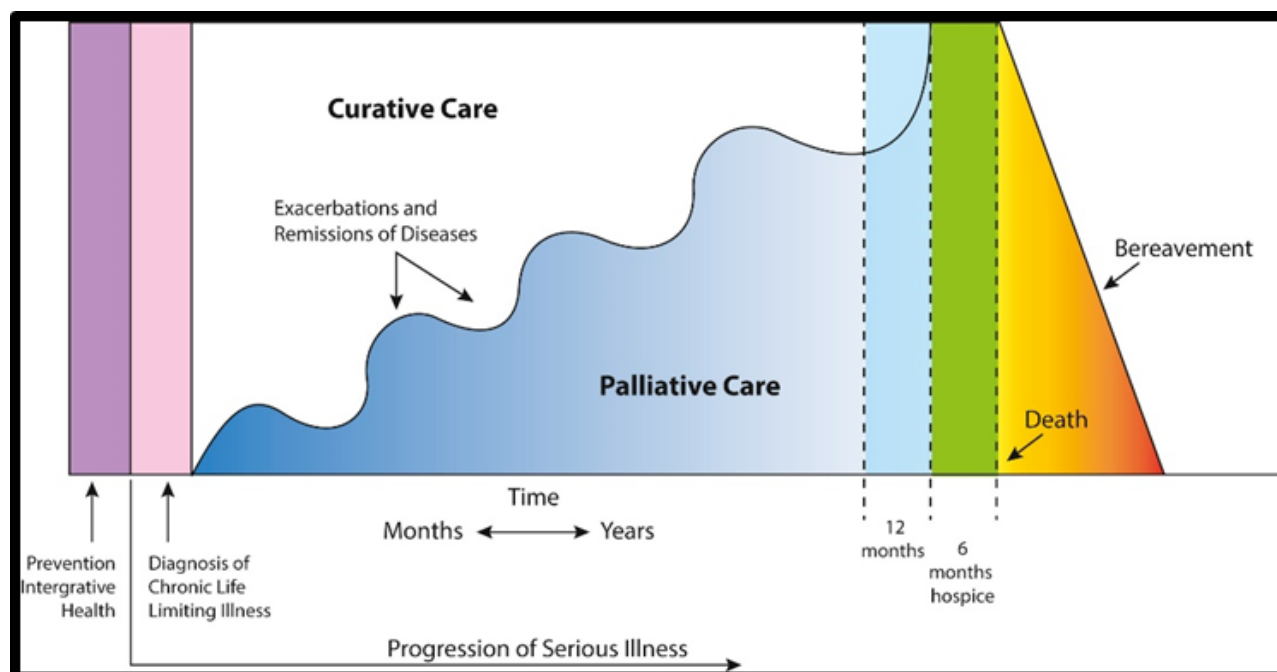
Palliative care is specialized medical care for people living with a serious illness.<sup>1</sup>

This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness (Figure 1),<sup>2</sup> and it can be provided along with curative treatment.

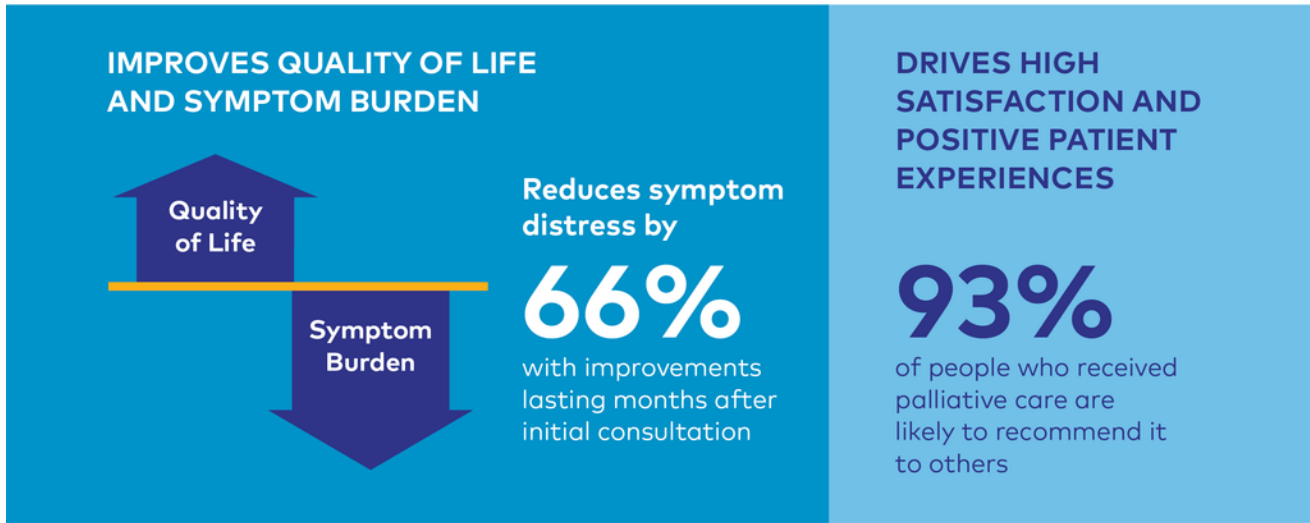
There is a strong evidence base supporting that palliative care positively impacts health care quality, patient satisfaction, and care outcomes (Figure 2).<sup>3,4</sup> Furthermore, by matching care to patient's goals and proactively addressing physical symptoms, it can help reduce avoidable and unwanted health care utilization (Figure 3).<sup>5,6,7,8,9</sup>

**Figure 1: Palliative Care in the Serious Illness Trajectory**



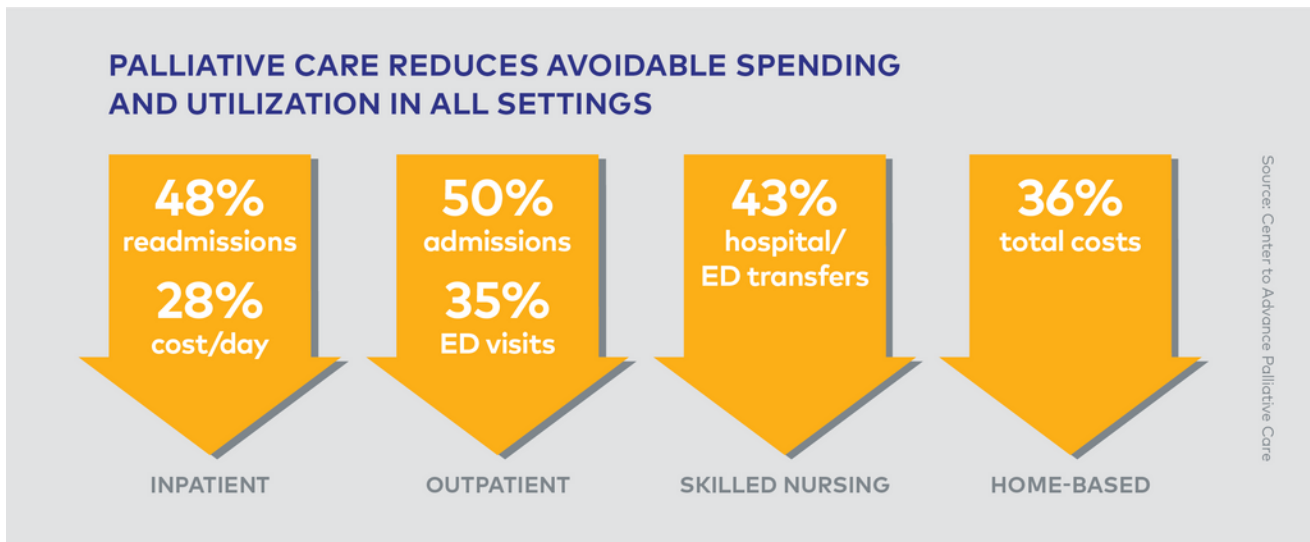
Source: Roth AR, Canedo AR (2019)

**Figure 2: Palliative Care Impact on Quality of Life**



Source: Center to Advance Palliative Care)

**Figure 3: Palliative Care Impact on Health Care Utilization**



Source: Center to Advance Palliative Care



## **The Relationship between Palliative Care and Hospice**

There is often confusion between palliative care and hospice, particularly since both share the goal of providing support and comfort to people living with serious illness and their loved ones. The main difference is that palliative care is appropriate for all patients living with serious illness, regardless of whether they are expected to make a full recovery or eventually transition to end of life. Meanwhile, hospice is a specific type of palliative care that provides holistic, interdisciplinary care to patients who have a limited prognosis (e.g., the Medicare Hospice Benefit specifies a prognosis of six months or less).<sup>10</sup> Hospice providers are expert in delivering end-of-life care, and hospices can provide a greater level of care than would be available earlier in the disease process with palliative care.

Ultimately, palliative care and hospice sit on the same continuum of care. When done well, palliative care can help improve quality of life during serious illness until the patient recovers (and into survivorship), or ease the transition to hospice when the disease becomes terminal. Please see the Glossary in Appendix C for more definitions.

# Council History and Charge

In 2017, Nebraska Governor, Pete Ricketts signed the Palliative Care and Quality of Life Act<sup>11</sup> (introduced by Senator Mark Kolterman as LB 323 in January 2017), Statute § 71-4501 through 71-4504, into law. The law established two entities:

**The Palliative Care Consumer and Professional Information and Education Program**, in which the Nebraska Department of Health and Human Services (NE DHHS) provides key palliative care information via its website,<sup>12</sup> including:

- Continuing education opportunities regarding palliative care for health care professionals;
- Delivery of palliative care in the home and in the primary, secondary, and tertiary environments;
- Best practices in palliative care delivery;
- Educational materials for consumers of palliative care; and
- Referral information for palliative care.

**The Palliative Care and Quality of Life Council (Council)**,<sup>13</sup> which consults with and advises NE DHHS on matters relating to palliative care initiatives. The nine-member council includes physicians and nurses certified under the Hospice and Palliative Medicine Certification Program, administered by the American Board of Internal Medicine and other experienced palliative care professionals (see Appendix A for the Council Roster).

As the Council enters its fifth year (see Appendix B for a list of past meetings), this report provides an opportunity to share its progress and make recommendations for future work. The Council's goal is to ensure that all Nebraskans living with serious illness have access to high quality palliative care that will both improve their quality of life, and potentially reduce avoidable emergency department and hospital visits, as well as other unwanted care.

# The Current Palliative Care Landscape in Nebraska

Per The Commonwealth Fund (2017),<sup>14</sup> approximately 9 percent of Nebraskans aged 18+ living in the community were classified as “high need.” High need was defined as adults who have three or more chronic conditions, and a functional limitation in their ability to care for themselves or perform routine daily tasks. This definition largely intersects with the definition of “serious illness” used to determine palliative care eligibility; namely, “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 caregivers.”<sup>15</sup> Examples include (but are not limited to) cancer, congestive heart failure (CHF), or chronic obstructive pulmonary disease (COPD).

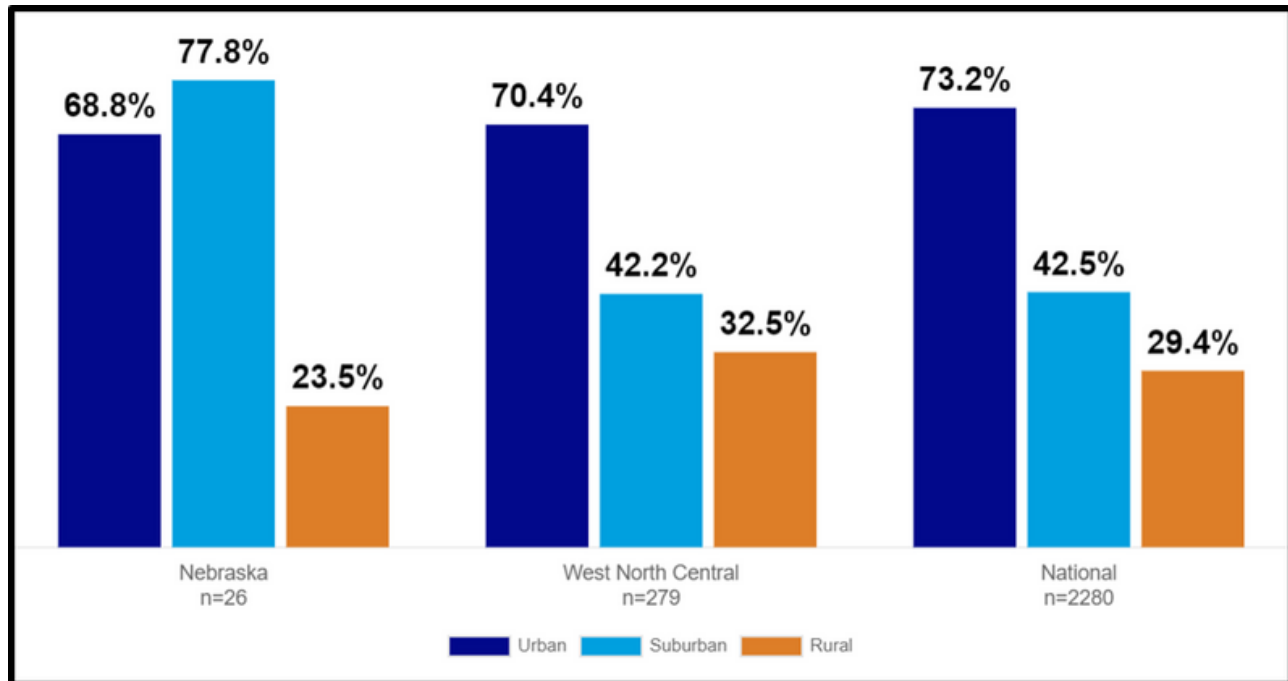
At the national level, there has been dramatic growth in the availability of hospital-based palliative care over the last 20 years. However, Nebraska was one of the few states that dropped a grade on the Center to Advance Palliative Care’s State-by-State Report Card, from an “A” in 2015 to a “B” in 2019. Additionally, as a rural state, there are significant disparities in access to palliative care based on geography, with the majority of palliative care services concentrated in Omaha and Lincoln.

**Table 1: Hospital Palliative Care in Nebraska**<sup>16</sup>

Location	2019 Grade*	By Hospital Size			
		< 50 beds (self-reported)	50-150 beds	151-299 beds	300+ beds
State	77.8% B	29.3% (12/41)	60.0% (6/10)	100.0% (4/4)	100.0% (4/4)
Region	71.8% B	35.0% (139/397)	51.0% (50/98)	84.1% (37/44)	100.0% (53/53)
National	71.5% B	36.3% (557/1535)	51.1% (474/928)	75.6% (578/765)	93.7% (671/716)

\*Grade does not include hospitals with <50 beds

**Figure 4: Percentage of Nebraska Hospitals with a Palliative Care Program by Geographic Type<sup>17</sup>**



Although Nebraska fares moderately well on hospital-based palliative care as compared to the rest of the country, there are disparities in access based on geography and hospital size. Furthermore, community-based palliative care remains limited, with only a handful of programs reporting home-based palliative care in three counties (Buffalo County [Kearney], and Douglas and Sarpy Counties [Omaha]). Finally, the Center to Advance Palliative Care (CAPC) reports that there are 2.6 certified prescribing palliative care providers (MDs or APRNs) per 100,000 residents in Nebraska.<sup>18</sup>

Nationally, it is estimated that approximately 5% of people who need palliative care receive it. Referencing the data above, it is clear that Nebraska has room to grow to ensure sufficient palliative care access for all residents living with serious illness.

# Council Accomplishments

Over the last four years, the Council led several activities to increase palliative care awareness, and build a foundation for future work. Key activities and accomplishments include:

**Launching the NE DHHS Website.** The NE DHHS Palliative Care website<sup>19</sup> went live in June 2018. Its main page includes background information on what palliative care is; where Nebraskans can find palliative care services; resources for patients and families; resources for pediatric patients; and provider resources, including continuing education opportunities, a list of professional associations, and a link to free COVID-19 resources for palliative care providers. The website also includes FAQs<sup>20</sup> on palliative care and a “Palliative Care Council” page<sup>21</sup> that includes Council meeting proceedings, presentations, and publications.

**Opioid Position Paper.** The issue of opioid access and prescribing is highly relevant to the care of people living with serious illness. As every state across the country has taken necessary steps to address the opioid/substance use disorder epidemic, it is critical to ensure that patients living with serious illness have appropriate access to the medications that preserve their quality of life. Therefore, in July 2019, the Council published an Opioid Position Statement,<sup>22</sup> which builds on the excellent work of the Nebraska Legislative Office<sup>23</sup> by recommending “a balanced, evidence-based policy approach that will address the underlying causes of the opioid crisis while preserving access for patients in need.”

**Provider Awareness.** To continue expanding palliative care awareness, the Council began working on a strategy to introduce palliative care to the relevant health care licensing boards<sup>24</sup> in Nebraska. Key presentation topics included:

- Introduction to palliative care and serious illness
- Core palliative care skills for all health professionals
- Importance of identifying patients in need of specialty palliative care
- Where to find more information

(See Appendix D for an example presentation.) The Council scheduled 14 meetings, but was only able to present to the Board of Mental Health Practice (March 2020) prior to the COVID-19 pandemic. The Council resumed these presentations in late 2021, and will continue through 2022.

**Working to Update the Palliative Care Definition.** In the state of Nebraska, palliative care is currently defined under the Hospice Licensure Act, which – at best – may perpetuate misconceptions that it is only appropriate for people at the end of life; and – at worst – could create barriers to delivering non-hospice palliative care in the community. Nationally, other states have addressed this issue by placing palliative care definitions and standards in other areas of state code;<sup>25,26</sup> one state passed a law that created a pilot that enabled hospices to be able to deliver non-hospice palliative care.<sup>27</sup>

The Council began meeting with representatives from NE DHHS to identify potential regulatory solutions to ensure that palliative care can be delivered to all patients based on their need, regardless of their diagnosis, prognosis, setting of care, etc. State officials identified possible strategies, including changing the palliative care definition in the Hospice Licensure Act, or amending the overarching Health Care Facilities Act to contain a palliative care definition. Again, these discussions were put on hold due to the COVID-19 pandemic, but the Council intends to resume these discussions in 2022.

**Relationship Building.** Early on, the Council recognized that the work of improving palliative care access and quality will require building partnerships across the state. Since the Council’s inception, members have met with representatives from (in alphabetical order):

- American Cancer Society Cancer Action Network, Nebraska, which was instrumental in establishing the Council
- Nebraska Cancer Coalition, which also presented to the Council in November 2019
- Nebraska Hospice and Palliative Care Association
- Nebraska Hospital Association
- University of Nebraska Medical Center, which recently created a fellowship program in hospice and palliative medicine<sup>28</sup>(and presented to the Council in 2021)

To increase participation, the Council voted in February 2020 to provide an option for members of the public to attend meetings virtually (as well as in person) using video and audio conferencing. This has enabled representatives from these organizations, as well as other stakeholders, to listen to proceedings and provide input.

Finally, the Council was pleased to welcome Governor Ricketts in August 2019 to share an initial assessment of the palliative care landscape in Nebraska and discuss early priorities for action. Governor Ricketts expressed support for the Council and provided suggestions for how it could increase public awareness of and/or support for palliative care.



# Challenges in Expanding Palliative Care

As the Council has assessed the palliative care landscape in Nebraska, it has encountered several barriers and challenges to expanding palliative care across the state:

**COVID-19 Pandemic.** The COVID-19 pandemic created significant disruptions to palliative care activities, as health care providers and other key stakeholders appropriately focused their attention on caring for patients and families who had been affected. The Council, which had previously met quarterly, reduced its meeting frequency in 2020 and 2021, and moved all meetings to virtual. Although the state is slowly transitioning back to “normal,” continued uncertainty around the virus and the work of addressing other priorities that had been paused during the pandemic may delay the Council’s progress.

That said, the COVID-19 pandemic has also created opportunities for palliative care. First, the pandemic has made it clearer than ever before that palliative care training is needed to care for people with serious illness. As the pandemic began to spread, specialty palliative care teams across the country saw unprecedented demand for their services – be it addressing the pain and symptoms (particularly breathlessness) caused by the virus, developing care plans for patients who tested positive, and/or providing a bridge between patients and families to communicate when in-person visits were not possible. Second, certain policies passed during the public health emergency – particularly flexibilities in telehealth payment and delivery – positively impacted the care of all people living with serious illness. People with serious or complex conditions, who found it difficult to leave their home even prior to the pandemic, were able to receive health care services that addressed their needs. This helped keep them safer during the pandemic and likely helped reduce avoidable emergency department visits. Furthermore, expanded use of telehealth has enhanced palliative care providers’ ability to reach patients in rural communities (see “Spotlight,” p. 18).



**Palliative Care Workforce and Programs.** As highlighted in the landscape section, access to specialty palliative care programs in Nebraska is limited and there are disparities based on geographic region. The creation of UNMC’s fellowship will help, but more work must be done to support the pipeline for palliative care specialists in the state of Nebraska, which can lead to the creation of more provider programs. Additionally, since there is not enough specialty palliative care to meet the current need in the state, it is increasingly clear that all health care professionals in Nebraska must be trained in the basics of pain and symptom management and communication.

**Palliative Care Payment.** One of the most significant barriers to growing palliative care access is insufficient reimbursement for services. In 2018, the National Academy for State Health Policy (NASHP) conducted a scan to identify how Medicaid programs pay for palliative care-related services.<sup>29</sup> Of the six identified, Nebraska Medicaid only reimbursed two: Advanced Care Planning and Home/Community Interdisciplinary Care Team Consult. Beyond fee-for-service billing (which is generally considered insufficient to support the model of palliative care that includes “non-billable” providers such as registered nurses, social workers, and chaplains), there is no Medicaid benefit in Nebraska that could support team-based care for adults living with serious illness, although this work is underway in several other states across the country. Finally, more work is needed to understand: 1) how palliative care can be incorporated (i.e., paid for) under existing Nebraska programs such as home- and community based services or managed long-term services and supports; 2) other ways in which Nebraska Medicaid managed care plans and commercial health plans are currently supporting and/or could better support palliative care for their beneficiaries.

**Public Awareness.** National research has found that, when educated on what palliative care is, 92 percent of people want it for themselves and their loved ones. Unfortunately, there continue to be significant misconceptions among both patients and providers around what palliative care is and who can access it.<sup>30</sup> While the NE DHHS website is a first step to creating a centralized place for information, more proactive outreach is needed to communicate to all Nebraskans what palliative care is and how they can access it.

# Spotlight: Palliative Care and Telehealth

The expansion of telehealth delivery and reimbursement has not only helped combat the COVID-19 pandemic, it has also increased palliative care access to some of the most vulnerable patients in Nebraska. Dr. Andrew Macfadyen from Children’s Hospital & Medical Center in Omaha reported that, prior to the pandemic, his palliative care clinic had the highest no-show rate for the entire hospital at 50%. Following the expansion of telehealth, the no-show rate dropped to 0%. “For many of the children we see, it can be difficult for them to leave the house for appointments because of the amount of medical technology they need. Furthermore, some of our patients live upwards of four hours away – making a single in-person appointment a multi-day affair. The expansion of telehealth presents a huge opportunity for better care, and we would like to see it continued.”

As the state continues to explore options to preserve the new telehealth flexibilities, it is important to note that supportive policies will need to go beyond reimbursement. For instance, many locations (e.g., the Sandhills) have insufficient broadband access to support videoconferencing that can be beneficial in palliative care encounters. Therefore, the Council urges policymakers to take a holistic look at telehealth expansion policies that include internet and technology access, to better support all Nebraskans living with serious illness.

# Future Council Activities and Recommendations to Health Care Leaders

Looking ahead, the Council plans to build on the progress of its first few years by:

- Growing Council engagement by:
  - Expanding Council membership to include additional perspectives, with a focus on expertise in payment, health equity, and rural health
  - Proactively reaching out to other palliative care and related stakeholders across the state to participate in Council proceedings
  - Inviting programs to share their work at regular Council meetings
- Revising and relaunching Council workgroups to ensure that priorities are advanced between regular Council meetings
- Rescheduling presentations with relevant Nebraska licensure boards to increase professional awareness of palliative care
- Identifying and/or developing and sharing additional educational materials to support palliative care professionals (e.g., education to help palliative care providers understand how they can appropriately bill for their services using existing codes), and continuing to update the website

Beyond that, the Council hopes to work closely with state health officials, policy makers, and other interested stakeholders to advance the following recommendations:

- Update the definition of and create standards for palliative care. Not only is this critical for access, as previously described, but standards are essential for creating a foundation for quality care. The Council will continue to explore regulatory options, but requests additional support from DHHS and/or the Legislature to identify options that could accelerate progress on this work

- Preserve telehealth flexibilities that were passed under the PHE (including policies that reimburse for these services at the same level as face-to-face visits) until more information becomes available
- Value suggested additional fee-for-service Medicaid codes to support palliative care-related services; begin exploring the possibility of a specialty palliative care benefit
- Explore opportunities to integrate palliative care into existing Medicaid managed care plan offerings for Nebraskans with serious illness (e.g., in Home and Community-Based Services)
- Convene a palliative care summit to identify opportunities and develop a statewide plan to advance palliative care access and quality. Participants should include (but are not limited to):
  - Nebraska state officials, including policy makers and representatives from the Department of Health and Human Services (particularly Medicaid and Long-Term Care), the Department of Insurance and Nebraska health plans, the Public Service Commission, etc.
  - Public and County Health Departments
  - The Nebraska Palliative Care and Quality of Life Advisory Council
  - Nebraska health care and provider associations such as the Nebraska Hospice and Palliative Care Association, the Nebraska Rural Health Association, the Nebraska Cancer Coalition (NC2), etc.
  - Palliative care and hospice program representatives
  - Universities and medical centers with palliative care offerings
  - State programs to support aging adults (e.g., Area Agencies on Aging)
  - Non-profit organizations supporting people living with serious illness (e.g., American Cancer Society, American Heart Association, National Kidney Foundation, AARP-NE, etc.)
  - Other interested stakeholders
- Hold periodic legislative hearings on the status of serious illness care in Nebraska. These hearings can include a review of reports produced by the Nebraska Palliative Care and Quality of Life Advisory Council, an overview of palliative care and its benefits, workforce development for supporting serious illness and payment policy for expanding access to palliative care services

# Conclusion

While Nebraska offers some palliative care, there are significant gaps in access based on geographic region and other factors. There are numerous opportunities to build on the current foundation by growing partnerships, removing regulatory and technological barriers, and exploring payment mechanisms to support palliative care delivery. The Nebraska Palliative Care and Quality of Life Advisory Council looks forward to continuing to work with public and private partners across the state to ensure that all Nebraskans living with serious illness receive care that supports good quality of life.

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# Appendix A - Council Roster

Listed in alphabetical order; see the "Palliative Care Council" webpage (<https://dhhs.ne.gov/Pages/About-Palliative-Care.aspx>) for current list of Council members.

<b>Name</b>	<b>Term</b>
Holly Adams, MSW	2017-2020
Marcia Cederdahl, BS, RN, CHPN	2017-present
Jennifer Eureka, CSW	2017-2018
Theresa Jizba, DNP, AGACNP-BC, ACHPN	2022-present
Brenda Kastens, MA, LMHP	2021-present
Stephen Lazowitz, MD	2017-2018
Andrew Macfadyen, MD	2017-present
Julie Masters, BA, MA, PhD	2021-present
Lori Molzer, RN, CHPN	2019-2020
Angela Mortenson, BA, MSW	2021-present
Linda Rock, BA	2017-2020
Todd Sauer, MD ( <i>current Chair</i> )	2017-present
Sabrina Schalley, LCSW	2017-present
Stacie Sinclair, MPP, CSW ( <i>current Vice-Chair</i> )	2017-present
Denise Woolman, RN	2019-2020



# Appendix B - Historical Meeting Dates

See the "Palliative Care Council" webpage (<https://dhhs.ne.gov/Pages/About-Palliative-Care.aspx>) for meeting agendas and minutes.

## **Meeting Date**

October 30, 2017

February 16, 2018

May 7, 2018

August 6, 2018

November 5, 2018

February 4, 2019

May 6, 2019

August 12, 2019

November 4, 2019

February 3, 2020

August 31, 2020

March 29, 2021

August 16, 2021

December 6, 2021

March 7, 2022

# Appendix C - Glossary

**Hospice:** “Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well.”

“Hospice focuses on caring, not curing and in most cases care is provided in the patient’s home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.” ([NCP Guidelines](#), [NHPCO](#))


**Palliative Care:** Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. ([CAPC](#))

**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](#), [Bollens-Lund](#))

**Telehealth:** “The delivery and facilitation of health and health-related services including medical care, provider and patient education, health information services, and self-care via telecommunications and digital communication technologies. Live video conferencing, mobile health apps, ‘store and forward’ electronic transmission, and remote patient monitoring (RPM) are examples of technologies used in telehealth.” ([NEJM](#))

# Appendix D - Sample Board Presentation

A decorative graphic featuring three circles of varying sizes and colors (grey, dark brown, and yellow) on the left, and a dandelion seed head with seeds blowing away on the right, set against a blurred green and yellow background.

**Introduction to Palliative  
Care in Nebraska**

Prepared for the Board  
of Mental Health  
Practice  
March 6, 2020



## Presenters: Nebraska Palliative Care and Quality of Life Advisory Council

MARCIA CEDERDAHL, RN, BS, CHPN  
RETIRED, CERTIFIED HOSPICE &  
PALLIATIVE CARE RN

STACIE SINCLAIR, MPP, CSW  
ASSOCIATE DIRECTOR FOR POLICY,  
CAPC

## NE Palliative Care and Quality of Life Advisory Council

- Consult with the NE DHHS on matters relating to palliative care initiatives.
  - Survey palliative care providers regarding best practices and recommendations
  - Work with the department
  - Make recommendations to the department regarding information on the [website](#) (“Palliative Care Consumer and Professional Information and Education Program”)
- Early Priorities:
  - Increase public awareness of palliative care and how it can support all people living with serious illness
  - Increase access to specialty palliative care in Nebraska
  - Educate all health care professionals in Nebraska on the importance of in basic palliative care skills

## What We'll Cover Today

---

Introduction to palliative care and serious illness

---

Core palliative care skills for all health professionals

---

Importance of identifying patients in need of specialty palliative care

---

Where to find more information

## What is Palliative Care?

Palliative care is specialized medical care for individuals living with a serious illness. This type of care is focused on providing **relief from the symptoms and stress of a serious illness**. The goal is to **improve quality of life** for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. **Palliative care is based on the needs of the patient, not on the patient's prognosis**. This care is appropriate at **any age and at any stage in a serious illness**, and it can be **provided along with curative treatment**.



## 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.

## Palliative Care is Appropriate For

Pediatric serious illness

Alzheimer's Disease and Related Dementias

Cancers

Chronic Obstructive Pulmonary Disease

Congestive Heart Failure

Kidney Disease

Stroke

Etc.

## 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



## What Does the Palliative Care Team Do?

### The palliative care team will:

- Relieve symptoms and distress
- Help better understand the disease and diagnosis
- Help clarify treatment goals and options
- Understand and support ability to cope with illness
- Assist with making medical decisions
- Coordinate with other doctors

## FAQs

- Where do people receive palliative care?
  - Palliative care is provided in a variety of settings, including the hospital, outpatient clinic, and at home.
- Does insurance pay for palliative care?
  - Most insurance plans, including Medicare and Medicaid, cover palliative care.
- How do I know if palliative care is right for my patient/client?
  - Palliative care may be right for someone if they suffer from pain, stress or other symptoms due to a serious illness.
- What can patients/clients expect from palliative care?
  - They can expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care helps patients carry on with their daily life. It improves their ability to go through medical treatments. It helps them better understand their condition and their choices for medical care.
- How does palliative care work with treating providers?
  - The palliative care team works in partnership with the treating provider(s) to provide an extra layer of support for the patient and family. The team provides expert symptom management, extra time for communication about their goals and treatment options, and help navigating the health system.

What Does This  
Mean for the  
Patient?

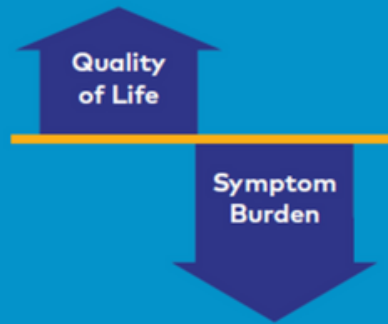
For the  
Caregiver?

For the Health  
Care  
Professional?





**IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN**



Reduces symptom distress by

**66%**

with improvements lasting months after initial consultation<sup>1</sup>

**DRIVES HIGH SATISFACTION AND POSITIVE PATIENT EXPERIENCES**

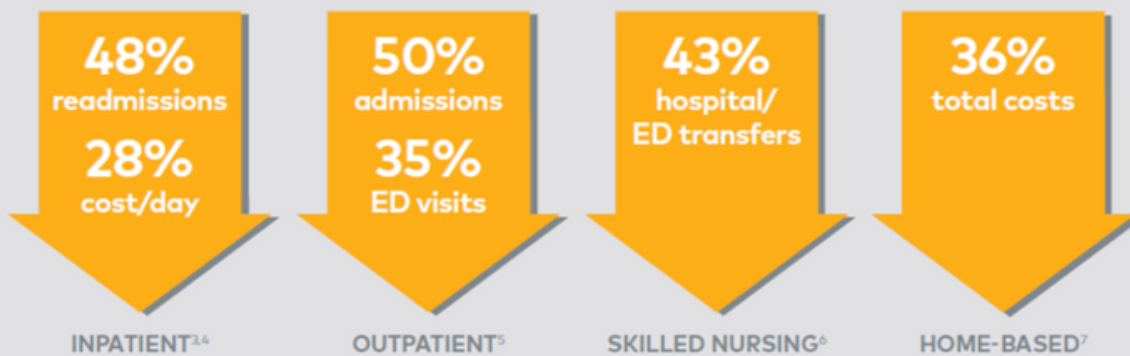
**93%**

of people who received palliative care are likely to recommend it to others<sup>2</sup>

Palliative Care Ensures Value

12

**REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS**



Palliative Care Ensures Value

13

## The Case for Communication and Symptom Management Skills

More people are living longer with serious and complex illness

Today's fragmented health care system makes it difficult to treat the person behind the disease

Consequences include unnecessary health care utilization and poor quality of life

## Two Things Are Critical to Improving the Situation



INITIATING MEANINGFUL COMMUNICATION WITH PATIENTS/CLIENTS ABOUT WHAT MATTERS MOST



PROVIDING SYMPTOM RELIEF, EDUCATION, AND OTHER SERVICES TO IMPROVE QUALITY OF LIFE

## How Training Helps



Improved patient experience



Safer practices



Reduced hospital days and patient spending due to advance care planning



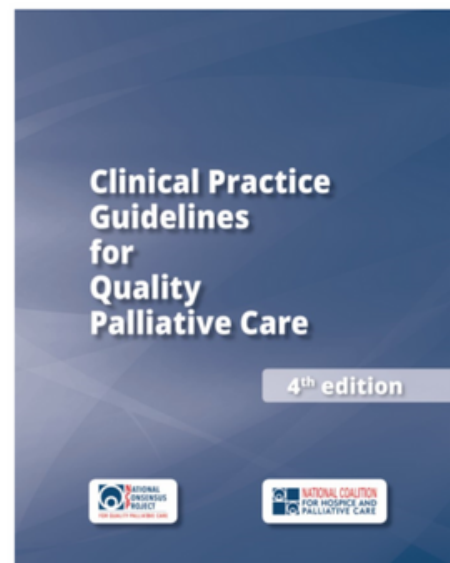
Less staff burnout



Reduced unnecessary hospital utilization

## The 4<sup>th</sup> edition

- For all people with serious illness, regardless of setting, diagnosis, prognosis, or age
- Funded by the Gordon and Betty Moore Foundation
- Published by the National Coalition for Hospice and Palliative Care
- NCP leadership consisted of 16 national organizations



## Domains of Palliative Care

Domain 1: Structure and Processes of Care

Domain 2: Physical Aspects of Care

Domain 3: Psychological and Psychiatric Aspects of Care

Domain 4: Social Aspects of Care

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Domain 6: Cultural Aspects of Care

Domain 7: Care of the Patient Nearing the End of Life

Domain 8: Ethical and Legal Aspects of Care

## Domain 3: Psychological and Psychiatric Aspects of Care



- IDT addresses psychological and psychiatric aspects of care in the context of serious illness
- IDT conducts comprehensive developmentally and culturally sensitive mental status screenings
- Social worker facilitates mental health assessment and treatment in all care settings
- IDT communicates to the patient and family the implications of psychological and psychiatric aspects of care

## Domain 4: Social Aspects of Care

- Addresses environmental and social factors that affect patients and their families
- Social determinants of health have a strong influence on care outcomes
- IDT partners with the patient and family to identify strengths and address needs
- Social worker is essential to the IDT



## Domain 6: Cultural Aspects of Care



- First step is assessing and respecting values, beliefs and traditions
- Care plans incorporate culturally sensitive resources and strategies
- Respectful acknowledgment and culturally sensitive support for grieving practices is provided
- IDT members continually expand awareness of their own biases and perceptions

## Domain 8: Ethical and Legal Aspects of Care



- IDT applies ethical principles to the care of patients with serious illness, including honoring patient preferences, and decisions made by surrogates
- Surrogates' obligations are to represent the patient's preferences or best interests
- Familiarity with local and state laws is needed relating to:
  - Advance care planning
  - Decisions regarding life-sustaining treatments
  - Evolving treatments with legal ramifications (e.g., medical marijuana)

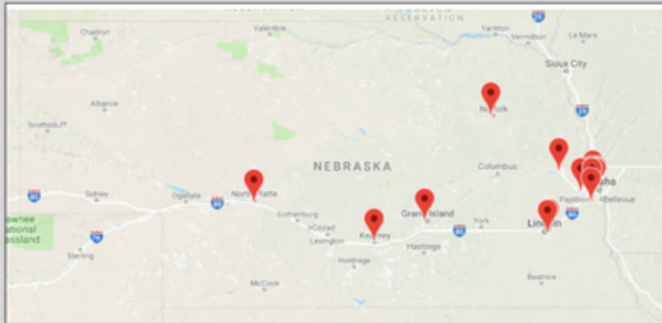
### Training Resources

- Center to Advance Palliative Care - <https://www.capc.org/training/>
- Vital Talk - <https://www.vitaltalk.org/>
- Stanford Palliative Care Training Portal - <http://palliative.stanford.edu/>
- Palliative Care Network of Wisconsin - <https://www.mypcnow.org/#!copy-network-resources/cxy/>
- Interpreting in Palliative Care Workshop Curriculum - <https://www.chcf.org/publication/interpreting-in-palliative-care/>
- Education in Palliative and End-of-Life Care (EPEC) - <https://www.bioethics.northwestern.edu/programs/epec/>
- End-of-Life Nursing Education Consortium (ELNEC) - <https://www.aacnursing.org/>
- California State Institute for Palliative Care - <https://csupalliativecare.org/>
- Palliative Care Leadership Centers - <https://www.capc.org/palliative-care-leadership-centers/>
- Palliative Care Education and Practice - <https://pallcare.hms.harvard.edu/>

# When is Specialty Palliative Care Needed?

-  Multi-morbidity
-  Intractable symptoms
-  Multiple ED visits/hospitalizations
-  Highly fragmented care
-  Complex family dynamics
-  Overburdened caregivers

## Palliative Care In Nebraska Hospital – 17 Sites



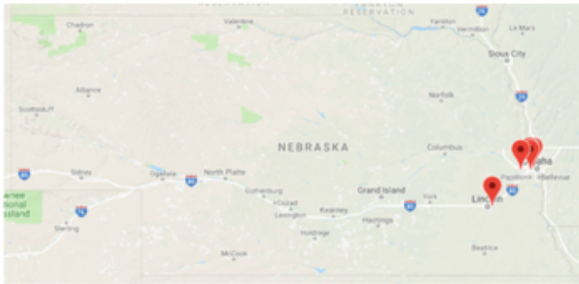
<https://getpalliativecare.org/provider-directory/>

- Alegent Creighton Health Lakeside Hospital
- Alegent Creighton Health Midlands Hospital
- Bryan Medical Center
- CHI Health Bergen Mercy
- CHI Health Creighton University Medical Center
- CHI Health Good Samaritan
- CHI Health Immanuel
- CHI Health Palliative Care Program
- CHI Health Saint Francis
- CHI Health St Elizabeth
- Children's Hospital and Medical Center
- Faith Regional Health Services
- Fremont Health
- Great Plains Health
- Nebraska Medicine - Nebraska Medical Center
- Nebraska Methodist Hospital
- Veterans Affairs Nebraska-Western Iowa Health Care System

# Palliative Care in Nebraska

Office/Clinic – 6 Sites

Nursing Homes – 6 Sites



<https://getpalliativecare.org/provider-directory/>

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## Nebraska DHHS Palliative Care

<http://dhhs.ne.gov/Pages/Palliative-Care.aspx>

A screenshot of the Nebraska Department of Health and Human Services (DHHS) website page for Palliative Care. The page features a dark blue header with the Nebraska logo and the text "DEPARTMENT OF HEALTH AND HUMAN SERVICES". Below the header is a navigation menu with links for Administration &amp; Support, Health Initiatives, Licensing &amp; Regulations, Healthcare Programs, Children, Families &amp; Seniors, Health &amp; Wellness, and Other Records. The main content area is titled "Palliative Care" and includes a "Subscribe For Updates" button, a paragraph of text defining palliative care, and a "Source: Center to Advance Palliative Care" link. There are also several expandable sections for "Nebraska Providers and Services", "Resources for Patients and Families", "Resources for Pediatric Care", and "Resources for Providers". A contact box for "Women's Health Initiatives Palliative Care Clinician" provides phone, fax, toll-free, email, and mailing address information.



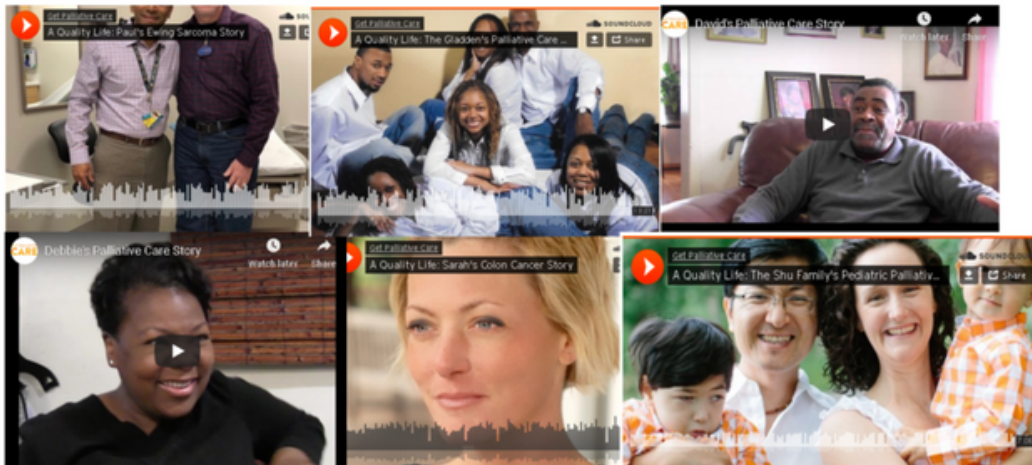
## Get Palliative Care



Are you or a loved one living with a serious illness? Palliative Care can help. Palliative care is specialized medical care focused on relieving the symptoms and stress of a serious illness. It is appropriate at any age and at any stage, and you can have it along with curative treatment. The goal is to improve your quality of life.

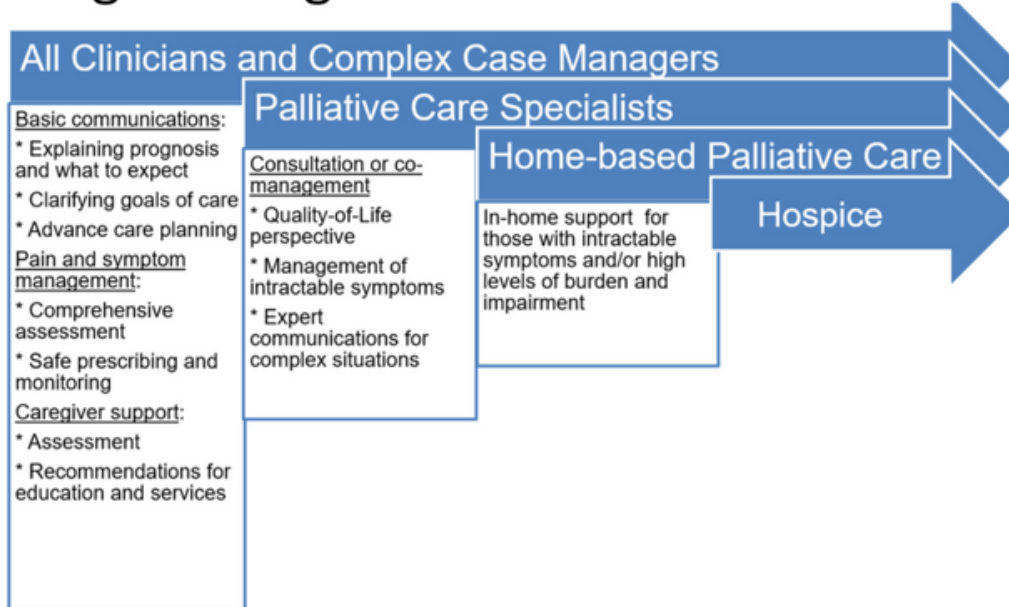
<https://getpalliativecare.org/>

## Patient Stories



<https://www.capc.org/palliative-care-patients-tell-their-stories/>

# Pulling It All Together



## Resources

- Nebraska Department of Health and Human Services (DHHS) Palliative Care Page - <http://dhhs.ne.gov/Pages/Palliative-Care.aspx>
- Nebraska Hospice and Palliative Care Association - <https://www.nehospice.org/page/A1>
- Center to Advance Palliative Care - <https://www.capc.org/>
- Medical Forms
  - Nebraska Emergency Treatment Orders - <https://nebraskaneto.org/>
- Legal and Financial Services
  - Legal Aid of Nebraska - <https://www.legalaidofnebraska.org/how-we-help/resources/elderly-aging/>
    - Free legal advice and assistance to NE residents 60+ through ElderAccessLine®
    - Services include: collections, Medicare/Medicaid, advance directives/living wills, simple wills, power of attorney, etc.
  - Patient Advocate Foundation - <https://www.patientadvocate.org/>

## Resources (cont'd)

- Recommended reading
  - *Being Mortal: Medicine and What Matters in the End*, Atul Gawande
  - *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death*, BJ Miller and Shoshana Berger
  - *When Breath Becomes Air*, Paul Kalanithi
- Conversation starters
  - The Conversation Project - <https://theconversationproject.org/>
  - Death Café - <https://deathcafe.com/>
  - Death Over Dinner - <https://deathoverdinner.org/>
  - Hello Game - <https://commonpractice.com/pages/versions>
  - Prepare for Your Care - <https://prepareforyourcare.org/welcome>
  - Aging with Dignity/Five Wishes - <https://agingwithdignity.org/>
- Additional links
  - Get Palliative Care – <https://getpalliativecare.org/>
  - AARP Caregiving Guide - <https://www.aarp.org/caregiving/prepare-to-care-planning-guide/>
  - Compassion and Support - <https://compassionandsupport.org/>

## Q&A



Questions for us?



What capacity does your Board have to promote palliative care?

Promotion (e.g., newsletter articles, blogs)  
Education to licensees  
Education to decisionmakers



What are the barriers that might get in your way?