GUIDE

NATIONAL HEALTH CARE *for the* HOMELESS COUNCIL

End of Life Care in Medical Respite Care Programs

2025

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Acknowledgements

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Introduction

The limited availability of adequate end-of-life care facilities is a growing problem for the general population, and there is even more concern about the lack of resources available for people experiencing homelessness (PEH). PEH often suffer from more chronic medical conditions and age at an accelerated rate. Age-related mortality ratios show that PEH in all age groups have a higher risk of death than most people of similar age in the general population.[1] The population of older adults experiencing homelessness is also rapidly increasing. This combination of factors highlights a need to increase and expand palliative and end-of-life care, also known as hospice care, into the homeless services continuum of care.

Differences among systems and complex medical and psychosocial barriers influence where health care takes place for PEH.[2] Presently, medical respite care facilities offer a solution to meet that need within communities. Also known as recuperative care, medical respite care is defined as acute and post-acute care for PEH who are too ill or frail to recover from a physical illness or injury on the streets or in shelter, but who are not ill enough to be in a hospital.[3] When addressing acute illness and psychosocial needs, medical respite care programs provide a short-term solution to these inequities.

For advanced diagnoses and terminal illnesses, not having a stable living environment can prevent individuals from receiving higher levels of care (e.g., end-of-life or hospice services), as this typically occurs in the home. PEH have additional disadvantages, including experiencing stigma and biases related to substance use and receiving adequate pain management. Medical respite care programs find themselves uniquely qualified to fulfill the need for end-of-life care for PEH due to their experience with the population, established community partnerships, and facility design. **The following guide offers program examples, established best practices, and ways to problem-solve potential barriers and challenges for medical respite programs to expand operations to begin providing end-of-life care support for PEH.** This resource was developed from research within the field, a review of literature, and with influence from service providers currently providing palliative and end-of-life care.

Palliative and End-of-Life Care

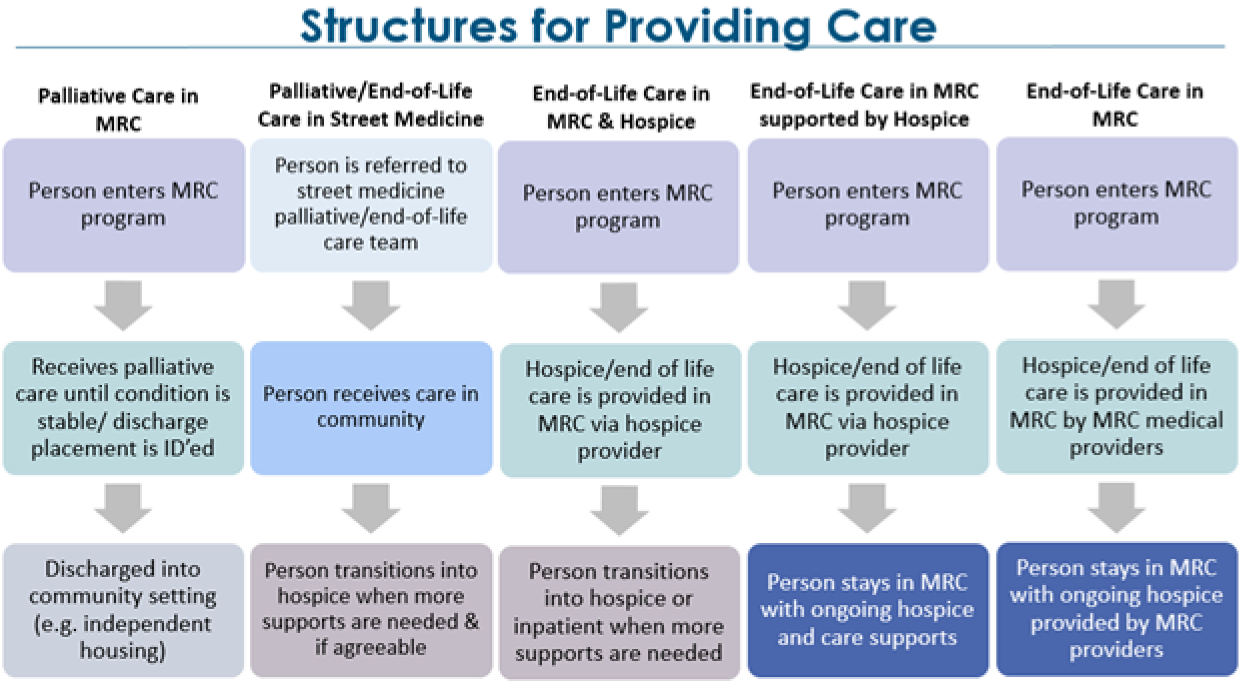
While often discussed together, palliative and end-of-life care are distinct approaches that require different skill sets, partnerships, and coordination of care to implement within programs. These care types also differ regarding the health outcomes for program participants.[4] For the purpose of this guide, the focus will solely be on providing end-of-life care in medical respite programs that are in partnership with a community hospice provider. Understanding the difference between the two types of care will provide context for the rest of this resource.

FIGURE 1 – DEFINING PALLIATIVE AND HOSPICE CARE[5]

Palliative Care	Hospice or End-of-Life Care
• An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. • This occurs through prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, including psychosocial ones.	• An approach that focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life. • The patient understands their illness is not responding to medical attempts to cure it or slow its progress. • Generally, hospice is provided for someone with a terminal illness who providers believe has six months or less to live.

In 2024, the National Health Care for the Homeless Council (NHCHC) completed an environmental scan that included interviewing established medical respite programs nationwide to learn from their experience with providing end-of-life care. While these programs differ in some approaches to service delivery, they often share many key characteristics. From those conversations, five program structures for providing palliative and end-of-life care were identified and are discussed in detail below (Figure 2). It is important to note that, like medical respite care programs in general, programs may not fit neatly within one classification or structure for care delivery. When incorporating end-of-life care services within a medical respite program, the focus should remain on fulfilling a need within an individual community. This resource will comprehensively explore two structures of providing care but will first offer an overall summary of each.

FIGURE 2 – STRUCTURE FOR PROVIDING END OF LIFE CARE



Each of the structures depicted in Figure 2 – Structures for Providing End-of-Life Care are based on how and where the program participant receives palliative or end-of-life care. The following section describes each in more detail.

Palliative Care in Medical Respite Programs

This structure focuses primarily on providing palliative care. Through this practice, a person receives a serious illness diagnosis with a palliative care plan and then is admitted into the medical respite program. During their stay, staff focus on pain and symptom management, treatment options, and the spiritual and emotional support needed post-diagnosis. The role of the program is to advocate for and support the program participant until a community discharge option becomes available, such as independent housing or assisted living.

Palliative and End-of-Life Care in Street Medicine

Within the next structure, palliative and end-of-life care is provided by street medicine teams with providers capable of providing palliative or end-of-life care. The need for street medicine teams to provide palliative and end-of-life care may be a result of a lack of settings in which individuals can receive this type or care or because of a person's preference to not go into a structured setting. Self-determination, or the ability to make choices about the things that affect one's life, is a crucial component of all social and healthcare systems. A person may choose to remain in their community, including remaining unsheltered, instead of entering a medical respite care program. Clinical care can be provided by the street medicine team until there is an agreement from the person to move into a medical respite program, inpatient facility, hospice facility, or other type of more supportive setting.

End-of-Life Care in Medical Respite Programs and Hospice

The first of the two most common structures for providing end-of-life care in medical respite programs is through partnerships with local hospice care providers. Within this structure, medical respite programs require a hospice partner from the community to assist in providing care to program participants. Once admitted into medical respite, the hospice partner comes on-site to implement the care plan, and additional support is provided by the medical respite program staff. Program participants receiving hospice care are then transferred to a higher level of care setting (e.g., hospice facility) as they near the end of life or when they require more support than can be provided by the medical respite team (such as support for activities of daily living [ADL]). This model may also be more appropriate for congregate settings or programs that are not able to provide private sleeping spaces.

End-of-Life Care in Medical Respite Programs Supported by Hospice

The second most common structure utilizes partnerships between the medical respite program and hospice providers. Here again, the hospice providers manage end-of-life care, and the medical respite program meets the person's remaining needs. This structure differs whenever the program participant's medical needs begin to progress. Instead of transitioning to a higher level of care, they remain in the medical respite program for the duration of their life. This structure is more feasible when the program is able to offer private sleeping spaces or has available caregiving support through outside agencies to address ADL needs. Regardless of the outcome, a hospice partner remains the primary clinical provider.

End-of-Life Care in Medical Respite Programs

The final structure identified does not require any community discharge option or hospice partnership unless the program participant needs or desires to move into a higher level of care. This model can only be implemented by programs with robust clinical staffing, as medical respite staff would be responsible for all clinical care from the time the participant enters the program until the end of life. Clinical care provided onsite includes medication prescribing, medication administration, and caregiving needs. An outside hospice provider can be consulted about the development of a care plan or other support, but they would not be providing any ongoing clinical services. However, other partnerships are still beneficial to address various needs around the end of life (such as caregiver organizations).

Determining the Need

When examining a medical respite program's feasibility of supporting program participants in end-of-life care, there are many factors to consider. The planning process can begin with completing a needs assessment of what resources are currently available in the local community. If a need for this level of care exists, initial steps should include locating a local hospice provider and identifying what level of support they can provide. Programs can also utilize multiple hospice agency partnerships if the need within the community is greater than what one agency can support, so as to provide more choices for those who need end-of-life care.

To consider if end-of-life care can be supported in your medical respite program, take time to answer the following questions:

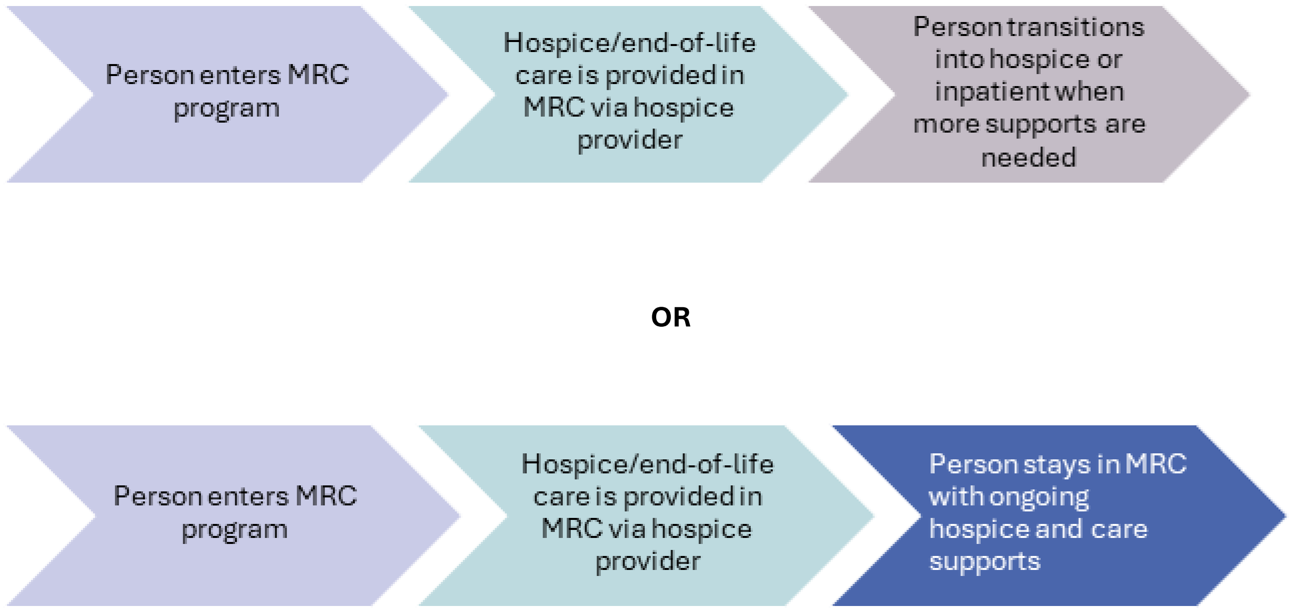
- What level of support can you provide for program participants for end-of-life care?
    - What are you able to do safely?
    - What would you need partners to do?
- Is your facility structured to support end-of-life care?
    - Do you have individual or more private, quiet rooms?
    - Is your facility ADA-accessible?
    - Can program participants be placed close to staff offices or areas?
- What would trigger the transition from your program to another space with more support?
    - What other organizations exist to transfer program participants to?
- Do you have staff to monitor the person's condition?
    - Does the hospice have a 24-hour call line?
    - What happens if the program participant decompensates overnight or while clinical staff are unavailable?
    - Do you have access to or capacity to support volunteers to fill any staffing gaps?

  - Do you have the capacity to implement additional staff training and grief support?

Addressing the Need

To further explore how to implement end-of-life care in medical respite, this guide will focus on structures 3 and 4 depicted in Figure 2, detailing how to support program participants through a partnership with a local hospice agency. Where these structures diverge, the medical respite program will need to determine if they will transition the program participant to a higher level of care or provide support for the duration of life. Figure 3 demonstrates how a person might move through services within each of these structures.

Figure 3 – Pathways of Receiving Care at End-of-Life In Medical Respite



If the program plans to discharge to another setting, they will need to outline how to identify when more support is needed for the program participant and what discharge options are available within the community. Alternatively, if the program provides care for the duration of life, they will need to adjust staffing and program operations to safely support the program participant. Each subsequent section in this guide offers a framework for the planning process and recommendations of best practices for the implementation of end-of-life care in medical respite programs.

Admissions and Assessments

Introduction

The provision of end-of-life care presents specific programmatic, clinical, and staffing needs. Medical respite programs and their hospice partners can meet those needs and provide excellent and comprehensive end-of-life care in the medical respite setting. In planning for the provision of end-of-life care, it is important to consider how services will be delivered, who will offer them, and who will receive them, including the following:

- Which end-of-life care services will be offered?
- Who will deliver those services, including identifying partnerships with other organizations?
- How will people be referred, assessed, and admitted to the program?
- What will be the process for transfers (in the event a person needs a higher level of care) or would there be a planned transfer to another facility when a program participant approaches the end of their life?

As a reminder, there are two program approaches or methods being considered in this toolkit:

1. A model in which a medical respite program partners with a hospice agency to provide end-of-life care in the respite setting up to the point at which the program participant, medical respite, and hospice teams determine that a higher level of care is needed or that the program participant is approaching death. The program participant is then transferred to a hospital or inpatient hospice setting.
2. A model in which a respite program partners with a hospice agency to provide end-of-life care in the respite setting up to, and including, the time of death.

The information presented in this section on program admission and assessment is applicable to both scenarios and should be tailored to each program's unique setup and needs.

Admissions processes must also center the goals and needs of the program participant receiving care and recognize that their goals and needs may change over the course of their illness and end-of-life journey. The development of an admissions process for end-of-life services ensures that individuals' needs can be met and that there are partnerships and pathways to meet needs that may extend beyond the medical respite setting. The following section outlines factors to consider when developing an admission process, including developing criteria based on the scope of service, an individual's needs, and collaborative agreements with external partner organizations.

Developing Admission Criteria

Developing criteria for admission to a medical respite program for end-of-life care begins with the menu of services currently available at the respite and with consideration of what could be provided as part of end-of-life care. Considerations include current staffing and potential changes to staffing models to meet hospice care needs, as well as what services could be provided through a partnership with a hospice provider, either on-site or in that provider's setting (i.e., hospital or inpatient hospice). Table 1 below can be used to identify potential needs for end-of-life care and questions to consider regarding if, and how, they can be met.

TABLE 1 – PROGRAM CONSIDERATIONS AND RESOURCES FOR PROVIDING END-OF-LIFE CARE

Service/Need:	**Provided by Medical Respite**	**Provided or Supported by Hospice Agency**
Storage of controlled substances	Where can medications be securely stored? Who has access? How are medications organized?	Consider that hospice comfort kits may need to be stored in a secure location and that some medications are intended for self-administration.
Administration of controlled substances (consider the potential for 24/7 needs)	When would staff who can administer medications be available? Can medications be accessed outside those hours? If so, how?	Consider mechanisms of communication with prescribing hospice providers if medication needs change acutely or change after regular business hours (e.g., the need for increased pain control).
Use of patient-controlled analgesia (PCA) devices	Will residents be able to use PCA devices for pain management while in the respite? (This can be a way to provide as-needed pain control outside of the hours administering staff are available.) Are there assessments for pain or sedation that will need to be completed by clinical or non-clinical respite staff?	Consider the role of the hospice partner in ordering the PCA, adjusting medication dosing, and changing the medication cartridge as needed.
Oxygen administration	Do current policies allow for administration of oxygen in the medical respite setting? What maintenance, storage, signage, and safety measures are needed to accept program participants on oxygen?	Consider not only the support of the hospice team but also communication and partnership with the oxygen supplier, who will provide support with resupply and troubleshooting.
Overnight staffing supports	Which staff provide overnight coverage to respite program participants? What is their capacity in terms of assessment and medication administration?	What is the 24/7 on-call number for the hospice? How would staff access those hospice representatives? Does the hospice have 24-hour in-person support, if needed?

	Who can be called upon to consult (internal staff or hospice providers), if needed?	
Wound care needs	Consider staff ability to conduct or support wound care, order wound care, and support self-management of wounds when possible. What is the maximum frequency of dressing changes a day that can be supported by medical respite staff? Consider staff capacity for wound care supply ordering through insurance, funds for uninsured needs, and where to store supplies.	What supports for wound care can the hospice team provide?
Private room or spaces	Will end-of-life program participants stay in a private room or with others? Are private spaces available for complex wound care or if someone becomes unable to get to the bathroom and needs a bedside commode?	Consider the criteria and process for transfer to a hospital or hospice setting, as needed, for increasing care or privacy needs.

Assessing for Program Fit

Once the menu of services has been identified, the criteria for admission can be determined. For example, if the program does not currently have capacity to manage oxygen, then those requiring oxygen therapy will not meet the criteria for admission.

Determine who can refer to the program (e.g., outreach team staff, permanent supportive housing or shelter programs, hospitals, primary care or specialty providers, or others).

Create a referral document to be completed by the referring entity. It is also important, if possible, to meet the potential participant prior to admission so staff can discuss the program parameters and available supports, including any processes for transfer to hospice or hospital-based care, and learn more about the potential participant's goals for the end of their life.

Consider the following areas described in Table 2 for inclusion in program referral documents:

TABLE 2 – CONSIDERATIONS FOR DEVELOPING PROGRAM REFERRAL CRITERIA

Inquiry Area	Specific Needs
Diagnoses	What is the terminal diagnosis and what other medical needs are present?
Medications	Are there controlled medications, medication dosing schedules, or as-needed (PRN) medications? What are the medication storage needs?
Oxygen	Does the person require oxygen therapy? And in what instances (e.g., continuous, overnight, or as needed with exertion/ambulation)?
Durable Medical Equipment (DME)	What DME is needed (e.g., a CPAP machine, cane or walker, wheelchair, shower chair, etc.)?
Care Team	Who is the referring provider or entity? What other medical providers are involved in care (following the patient or prescribing medications)? What pharmacy provides the person's medications?
Hospice Provider	Has a hospice provider been identified or does the person need to be connected with hospice? Who is the hospice provider, and do they have an existing relationship with the medical respite program?
Self-Care and Activities of Daily Living (ADLs)	Is the person able to perform their ADLs and are there areas where they need adaptive supports to complete self-care? Do they use incontinence supplies and can they currently get to the bathroom independently?
Procedures Needed and Office Visits	Does the person have needs for which they will require transport (e.g., palliative radiation appointments, alternative therapies, or planned paracentesis)?
Advanced Directives	Does the person have a living will or health care proxy? Have they obtained a "Do Not Attempt Resuscitation" order as part of a hospice admission process?
Emergency Contacts	Who are the person's emergency contacts? Is their contact information up to date?
End-of-Life Goals	What does the person want for their end-of-life care (e.g., to be comfortable, to have family/friends present, to avoid the hospital, etc.)?
Substance Use	Does the person actively use substances? How could this affect their care and needs and is planning for treatment or other accommodations needed?

Assess whether the person's needs can be met in your program. It is often worth having additional conversations with the potential program participant and their current care team to better understand a response or to talk through program options. For example, many people may prefer not to die in a hospital; however, they may be willing to consider this if a hospice team is in place to ensure their comfort and manage the admission process. Other examples may include planning for how to address withdrawal in someone who no longer has the ability to leave the program to obtain alcohol or other substances on their own. (See the section on *Staff Training* to equip staff to address these needs.)

Referrals to a Higher Level of Care

The menu of services will also help to determine criteria for referral and transfer to a higher level of care. This will be done in partnership with hospice providers and will always be somewhat dependent on each program participant's needs. It is helpful to start with a set of criteria that would prompt referral to hospital-based or inpatient hospice care. For example:

- Program participant's pain cannot be controlled with options available in medical respite
- Program participant's dressing changes are needed >3 times daily
- Program participant is unable to perform ADLs or is bedbound
- Program participant is nearing the end of life and has agreed to the transfer
- Program is unable to control the program participant's other symptoms in respite (e.g., nausea/vomiting, bleeding, shortness of breath)
- Program participant is confused or disorientated, making them unsafe in the medical respite setting (e.g., leading to falls, etc.)

Admission Checklist

The following list can be used at admission to confirm all documents and care team members are in place and identified. The list can be tailored to reflect the needs of each individual medical respite.

☐ Referral documents completed and in file
☐ Referring provider documented with updated contact information
☐ Emergency contacts identified and documented
☐ Needed DME in place, including wound care supplies; if coming with the program participant, include details of delivery
☐ Current active medication list received
☐ Medications at respite; if being delivered, include details and contact information for pharmacy and delivery plan
☐ List of upcoming appointments, if any
☐ Behavioral health providers, if applicable; include documentation on medications like long-acting injectables (documentation of last and next dose) or buprenorphine, methadone, etc.

- ☐ Oxygen provider’s contact information, if applicable, and oxygen in place; if coming with the person, include details of the delivery plan
- ☐ Any other pertinent information for admission

Partnering with a Hospice Provider

Introduction

A key component of providing end-of-life care in medical respite programs is developing a partnership with a local hospice provider. While this is not imperative, such a partnership improves care delivery, balances the workload of respite staff through shared responsibilities with the hospice care team, and provides support if a program participant’s needs increase or transfer is necessary as the time of death approaches.

Medical respite providers should consider their desired end-of-life program setup, as well as the intended role for the hospice team. For example, is the plan for the hospice team to work with medical respite staff to provide on-site supports until the time of death, or will program participants transfer to an inpatient hospice or hospice-supported hospital setting as death approaches? It is important to think through decision-points and responsibilities (e.g., if acute pain management needs arise, will medical respite or hospice providers respond to order medication changes? Would the time of day impact responsibility?).

Another consideration in bringing in a hospice partner is that hospice is a valuable partner in end-of-life care well before a person is in their final weeks or days of life. Hospice providers can work with medical respite team members, family, or community members close to the program participant, as well as with other medical providers to provide education and consultation that will ease the participant’s journey as they *do* enter those final weeks. These conversations can be difficult, and there is often a misconception that the involvement of hospice means that death will come very quickly; while this is sometimes the case, it is certainly not the rule. Having a partnership with a hospice team can support both the medical respite care team as well as individual program participants who are facing a terminal diagnosis.

Developing and Defining a Partnership

Below are steps in the process and questions to consider when identifying and developing a partnership with a hospice provider.

Identifying a Partner Organization

Consider deepening a relationship with a hospice provider who has worked with your medical respite team informally or with individual medical respite program participants. Alternatively, identify a local hospice provider with a program model or facilities that align with the planned end-of-life model for your medical respite. Reach out with your interest in a partnership and set up a meeting to discuss your planned end-of-life services and explore what working together could look like.

Questions to consider:

1. What program approach do you intend to use?
    a. End-of-life care and death in place at the medical respite with hospice support
    b. Transfer to hospice or hospital setting based on symptoms or when death is imminent
    c. A different or hybrid approach
2. What role do you hope the hospice provider will play?
    a. Providing nursing, social work, and spiritual support
    b. Providing medication orders and pain management
    c. Providing on-call telephonic or in-person support to medical respite staff for program participants' acute needs
3. What does the medical respite team bring to the relationship?
    a. Safe and appropriate setting for end of life
    b. Staff supports (based on respite team makeup)
    c. Expertise in homelessness and care coordination for unhoused individuals
    d. Expertise in behavioral health needs among people experiencing homelessness

Establishing a Relationship

Once a partnership has been agreed upon, it will need to be formalized through a contract or memorandum of understanding. Determine who the main point of contact will be for both organizations and make sure staff at both organizations know who to go to with scope or service delivery questions.

Questions to consider:

1. Which type of agreement is best and what elements of service delivery will be covered by the agreement?
2. Which care elements will be handled by each organization and how will the two organizations communicate and formally collaborate (e.g., shared case conferences, shared or read-only access to electronic medical records, etc.)?

Determining Workflow and Responsibilities

While the agreement will establish how the two organizations will collaborate to provide comprehensive care, it will be important for frontline medical respite and hospice staff to understand the workflow and which organization will be responsible for common needs or scenarios.

Questions to consider:

1. Who will complete intake paperwork for the medical respite program and at what point in the process will hospice admission be completed?
2. Who is responsible for establishing the program participant's wishes for resuscitation and documenting a Do No Attempt Resuscitation (DNAR) order, if applicable? Where will this information be found for both medical respite and hospice staff?

3. Who will manage pain needs and medication orders? Note that this can sometimes be managed by multiple providers, depending on the medications (e.g., behavioral health providers may still write prescriptions for mental health medications, while hospice providers will write prescriptions for pain and other comfort medications).
4. Who will manage potential withdrawal needs (e.g., for a patient who, for medical reasons, can no longer leave the medical respite to obtain drugs or alcohol, or who has chosen to stop use upon entering medical respite care and is interested in treatment)?
5. How will acute needs outside of regular business hours be handled by the medical respite, and how will the hospice team support acute care needs (e.g., pain management needs or symptom management)? How will the medical respite team communicate with the hospice team when a need arises?
6. What will be the process for determining if a program participant is ready for or needs transfer to a different setting? What is the role for each organization and the program participant in that process?

Ongoing Staff Support

Both the medical respite and hospice teams will likely experience a learning curve working with each other, and there will be an initial and ongoing need for formal training on experiences of homelessness and end-of-life care for both teams. Medical respite staff will also need grief support following program participant deaths and could benefit from processes used in hospice to remember and say goodbye to participants. Consider the following training topics for cross-organizational training (refer to the *Staff Training and Support* section for more details):

- Experiences of homelessness and its effects on health and healthcare access
- Supporting individuals and families at the end of life
- Meeting behavioral health needs in medical respite settings
- Identifying and responding to an opioid overdose
- Staff wellness in hospice and palliative care settings

Staff Training and Support

Introduction

While providing end-of-life care is a beautiful gift to our program participants, it is important that we set our staff up for success when engaging in this work. Training and support can help offset the compassion fatigue and compounded grief innate to this work and provide staff with the skills and tools needed to thrive in their roles.

Foundational Staff Training Objectives

The foundational training recommendations below focus on providing staff and leadership with skills that are valuable across the spectrum of medical respite care, including but not limited to end-of-life care. The skills in these trainings can help staff navigate their own internal feelings that naturally come up when supporting someone through the end of their life, as well as the range of emotions that will come up for the patient.

There are a variety of mechanisms for training and various providers and experts who can train staff around topics related to end of life. This section outlines training topics and objectives or approaches within these topics related to providing end of life care. Programs can evaluate available resources and local experts who can provide trainings that meet the suggested objectives or approaches.

Behavioral Health Training Objectives

- To learn communication styles that are nonjudgmental, leverage active listening, and focus on collaboration with program participants
- To develop the ability to help program participants to recognize automatic thoughts that contribute to emotional distress and to reframe maladaptive thoughts to reduce distress and encourage more supportive outcomes
- To learn person-centered de-escalation
- To learn person-centered anger management
- To employ helpful self-soothing activities that use program participants' identified strengths (i.e., strategies that helped them get through prior challenging times)
- To develop a personal safety and well-being intervention plan
    - This is a plan that is developed upon admission, where with the help of a case manager, program participants identify how staff can best de-escalate and support the participant they are activated or agitated.

Additional resources to address behavioral health in a medical respite program:

- Medical Respite Online course series:
    - Introduction into Behavioral Health
    - Behavioral Health, Stigma, and Resilience: Firsthand Perspectives
    - Program Approaches to Supporting People with Behavioral Health Needs in Medical Respite Care
    - Strategies for Supporting People with Behavioral Health Needs in Medical Respite Care
- Addressing Behavioral Health and the Role of the Behavioral Health Consultant
- Person-Centered Risk Mitigation in Medical Respite Care
- Publication: Promising Practices: Providing Behavioral Health Care in a Medical Respite Setting

Healing-Centered Engagement Training Approaches, Adapted for End-of-Life Care

Healing-centered engagement is a strengths-based process that provides insight into the intricate factors that inform the choices people make throughout life and how they engage with others and with themselves. It builds upon the framework on person-centered care and makes a conscious effort to move beyond individual destabilizing events. It views healing as the restoration of identity, meaning, and purpose. It also allows us to incorporate peace. This approach understands that we are more than the struggles and strife we experience.

Here are central components of healing-centered engagement:

- Identity: Understand the significance that a participant's identity plays in their daily life and end-of-life journey.
    - We are all informed by narrative; that is, the story of our lives.
    - These narratives have an impact on a person's internalized identities.
    - Our identity informs and affects how we engage with others and navigate the world.
    - It is critical to understand personal experiences and reactions from a place of curiosity rather than judgement.
- Agency: the power to change our personal condition in any given situation. People may not be able to change the fact that they are dying, however, programs can facilitate agency in the process and circumstances surrounding their death.
    - Commit to discovering the direct strengths of people *and* adjacent strengths that can be developed to support dying with dignity.
    - Ask open-ended questions and allow space for response.

    - Affirm program participant's feelings, strengths, and worth as a fellow human being, and respect their needs for their end-of-life journey.
    - Employ reflective listening (i.e., repeating back what program participant has expressed).
    - Take what was expressed through reflective listening to confirm understanding of what supports a program participant has asked for and needs most during their end-of-life journey.
- Relationship: It is essential to understand what would feel like meaningful connection to the program participant. Having a connection to someone else during the end-of-life journey is important to many who are dying.
    - Prioritize connection before interventions!
- Meaning: It is a goal to support program participants in identifying where they found personal meaning and purpose in their life.
    - One helpful approach: Look for meaning in found in small and large acts. Like a pebble dropped into water, a small act can have rippling effects.
- Aspiration: What is the program participant's vision or goals for their end-of-life journey? How do they wish to be remembered?

Shared Humanity Training Objectives

- Cultivate an open attitude and take the time to learn about and honor other identities and experiences.
- Be mindful of the intersecting identities we all carry and the history that may go along with them.
- Resist the temptation to change others to become more like you or to conform to a single narrative of health and well-being.
- Turn to curiosity about what makes others unique.
- Recognize the person in front of you is an expert on their own life.
- Commit to becoming a life-long learner.
- Recognize and address power imbalances, such as between a provider and a program participant.
- Address internalized narratives, including language and practices that reinforce an "us vs. them" mindset.
- Address saviorism narratives of being the "only one who can help."

Person-Centered Responsive Care for End-of-Life Care Training Objectives

There are certain populations who may experience additional distress as they move through the dying process, including the following groups:

- War veterans
- People with lived experience of being chronically unhoused
- People with lived experience of PTSD or complex PTSD

Applying a person-centered lens to end-of-life care can help staff and participants navigate the complexities that may arise.

- Safety: Ensure the environment feels safe to the participant who is dying as much as possible.
- Choice: Allow and honor participants' choices along their end-of-life journey.
- Trust: Invest time to build relationship with participants.
- Compassion and Empathy: Always engage with participants from a place of shared humanity, including separating behaviors from the person and their value.

Person-Centered Risk Mitigation Training Objectives

End-of-life care is not the place to try to "cure" any behavior or practice. Rather, the goal is to decrease suffering as much as we can. Person-centered risk mitigation practices should be used to address physical, mental, emotional, and spiritual distress.

- Understanding the principles of person-centered risk mitigation: This is an approach that can be applied to any health behavior with the aim of reducing negative outcomes and increasing health and safety.
    - Lead with a nonjudgmental approach to the program participant's health behaviors and personal goals.
    - Begin where the program participant wants to start in terms of their health goals, often referred to as "meeting the person where they are."
    - Facilitate supports and interventions that help the program participant meet their goals (e.g., facilitating and supporting the use of nicotine patches for a person who wants to stop or reduce tobacco use).
- Open communication
    - Practice skills to engage program participants in conversations about substance use or other health behaviors that could affect their experience at the end of life.
    - Increase knowledge and comfort among staff so that they can talk with program participants about rules regarding substance use in the medical respite setting and how the care team can help (e.g., with withdrawal management medications or medications for opioid use disorder).

- Pain support: A big fear for those with a history of or current substance use is being in pain at the end of their life due to altered tolerances or pain thresholds related to substance use.
    - Prepare staff to be able to communicate with program participants and the hospice care team regarding participant concerns, pain needs, and changes in comfort and pain.
    - Prepare staff to be able to discuss safety and risk reduction for program participants who may be actively using substances and receiving medications for pain, including potential overdose response.

Understanding Perceptions Towards Hospice Care Considerations

- Navigating patient reluctance toward hospice care
    - Considerations: People are programmed for survival against all odds, so it can be hard to accept hospice.
    - Considerations: Medical mistrust can be a barrier to accepting care at end of life or accepting interventions like transfers to the hospital or inpatient hospice.
- Navigating the space between palliative care and hospice
    - Sometimes a person qualifies for hospice but is reluctant to engage with end-of-life care, while at the same time does not engage in care to help support prolonging their life (e.g., a person receiving dialysis who only attends one of three weekly treatments or a person receiving chemotherapy treatment who does not go to their appointments).

Health Care for the Homeless 101 Training

It is important that we see and understand the full spectrum of humanity for our program participants. One aspect is recognizing the holistic effect that being unhoused has on a person, including early aging and death at younger ages, compared to housed counterparts.

This training is available here.

End-of-Life Care Roles and Responsibilities Training Objectives

- Identify clear role responsibilities
    - What is the medical respite staff’s role in caring for the program participant?
    - What is the hospice staff’s role in caring for the program participant?
- Have a clear understanding of the intervention decision tree
    - What situations should be managed by following the guidelines outline in the *Preparing for and Responding to Death* section?
    - What situations would require a call to the hospice team?

  - How to identify when the level of care needs exceed the medical respite staff's capacity, including what the next steps are.
  - What situations (if ever) would require a call to 911?

Stages of Active Dying Training Objectives

Providing end-of-life care requires a mental shift for both the program participant and staff. When providing end-of-life care, healing looks like helping participants understand and navigate the dying process so that they die with dignity.

It is important that staff understand what is considered a natural stage of dying and how to support program participants during these times. This information can be found in the section titled *Preparing for and Responding to Death* in this guide. There are great affordable resources that medical respite programs can utilize to support staff in understanding the dying process better so they can respond in ways that feel supportive to participants, while also decreasing the effects on staff.

Additional Resources:

- *Gone from My Sight: The Dying Experience*, by Barbara Karns, describes the dying experience and is available in 14 languages
- *The Eleventh Hour: A Caring Guide for the Hours to Minutes Before Death*, by Barbara Karns, describes the journey of sitting with someone who is actively dying
- Demystifying Death Course, offered by Welcome Home Chattanooga
- Zen Caregiving Project, an online resource with courses to support and train caregivers in compassion-based approaches

Pain Management in End-of-Life Care Training Objectives

The dying process can bring about physical, emotional, mental, and spiritual pain. Pain management can range from pain medications to anxiety-reducing or calming medications. For program participants who have a history of substance use disorder, it is important that their history is taken into consideration when medications are being prescribed. What may seem like an adequate starting dose for people without a history of substance use may be actually insufficient dosing for a program participant with a history of substance use disorder. Information on considerations for pain management can be found in the section on *Medication Management.*

Supplemental Training Considerations

- Medications to relieve suffering during active stages of dying
- Medication management recommendation for program participants with a history of substance use disorder (see also the section on *Medication Management*)

Supporting the Mental, Emotional, and Spiritual Journey of Dying Training Objectives

Beyond the physical aspects of dying there are also mental, emotional, and spiritual aspects. More information can be found in the section titled *Preparing for and Responding to Death* in this guide. A death or grief doula is a great resource to partner with for this training.

Resources

- *Uplift My Life Today* podcast episode "Death and Dying Series"

Supplemental Training Considerations

- Anxiety and restlessness management in end-of-life care
- Psychosocial aspects of dying
    - Given and chosen family dynamics (e.g., understanding the psychology behind why families react the way they do):
        - This can include feelings of guilt, lack of control, or anger over the situation.
        - This can also include caregiver concerns. As end-of-life care can look very different from other medical care, caregivers and family may wonder why people aren't eating or being fed or may have fears of "overmedication."

Identifying and Honoring Last Wishes Training Objectives

Many in the field of hospice use the tool 5 Wishes to help participants identify what is most important to them. These can feel like difficult conversations to many. If your program has access to a social worker, chaplain, or death doula, consult with them, as they are often skilled in having these conversations. If your program doesn't have access to any of the above positions, then it will be valuable to provide a training session where staff can familiarize themselves with these tools and practice with each other or program participants who are willing to support a training.

When having these conversations, it is helpful to follow these basic guidelines:

- When possible, a staff person who has an established relationship of trust with the program participant should be leading the process.
- Go into the process expecting it to take two to four conversations to complete.
- Use these potential prompts to start the conversation:
    - "It's important to be the boss of your body, and this is how we get to learn that, so we can honor you in a way that is meaningful."
    - "Would you share your favorite memory with me?"
    - "How would you describe yourself in ten words or less?"
    - "Tell me about a skill that has served you well in life."

        - Follow up: “As you think of skills that have served you well, who would you say has the skills, attitude, and connection to you to make health decisions if or when you are no longer able to do so for yourself?” [Wish 1 of the 5 Wishes]
    - “Can you tell me about something that always makes you smile?”
    - “What do you love the most in your life?”
        - Follow up: “If you are no longer able to enjoy things you love in life because of your health, what do you want to make sure we do or don’t do?” [Wish 2 of 5 Wishes]
    - “Where is your happy place?”
        - Follow up: “If you are no longer able to tell us your needs, how do you want us to make sure you are comfortable?” [Wish 3 or 4 of 5 Wishes]
    - “What would you like to be remembered for most in life?” [Wish 5 of 5 Wishes]

Providing Support to Staff

While providing support to program participants at the end of their life is a gift, it can bring up a number of emotions. Below is a list of supportive practices that other medical respite programs providing end-of-life care find beneficial:

- Normalizing the unpredictability of dying
- Having leadership with experience or who genuinely understand the work
- Team-building and debriefing together
- Normalizing compassion fatigue: This can look like routine or scheduled compassion fatigue check-ins.
- Being mindful of hero syndrome: This can look like watching for language or practices demonstrating that someone believes that “I'm the only one who understand or can meaningfully support” a particular program participant.
- Participating in group and self-identified post-death rituals: This can look like hosting a group memorial service at regular intervals, taking a moment to acknowledge the passing of life, or bathing the body while waiting for the funeral home to arrive.
- Bringing in a grief counselor on standby as needed for intense cases
- Offering counselor support for compounded grief and complicated emotional responses
- Normalizing mental health days

Adjunct Support Staff Roles

Programs can also use adjunct staff who can fulfill certain supportive roles for program participants and for staff. These roles are discussed in Table 3:

TABLE 3 – SUPPORTIVE STAFFING AND ROLES FOR END-OF-LIFE CARE

Role	Description	Benefits
Death Doula	Someone who assists a dying person and those close to them by providing emotional and physical support, education about the dying process, preparation for what is to come, and guidance while people are grieving.	Spends time with people and helps to address spiritual and emotional needs. Supports staff's grief and challenges that arise doing end-of-life care. Value of grief rituals lead by someone skilled in navigating end-of-life dynamics.
Spiritual Community Connections	This can be a volunteer chaplain, priest, rabbi, nun, monk, or other spiritual practitioner who provides as-needed support to program participants in need of spiritual support or who are experiencing spiritual distress.	Staff may not have the time, bandwidth, or knowledge to support the spiritual needs that come with end-of-life care. Having someone come in intermittently who can provide this care can help decrease program participants' spiritual distress, which can contribute to agitation.
Volunteers through No One Dies Alone (NODA)	The volunteer support can range from general companionship to specialized music and arts therapist, social work, occupational therapist, and nursing students. Provides program participants who are interested with a volunteer to be with them during their final days.	Allows program participants to have someone with them when they die.

Case Management and Care Coordination

Introduction

While medical respite team members are accustomed to the coordination of medical, behavioral health, and housing services for medical respite program participants, supporting people at end of life presents unique needs that may be new for staff. This section outlines several areas of need specific to end-of-life care and provides information on meeting those needs.

Care Coordination at End of Life

Medical respite program participants receiving end-of-life care will have many of the same care coordination needs as other medical respite residents:

- Coordination of medical appointments
- Communication with primary care, behavioral health, and other specialty providers
- Arrangement of transportation services
- Supporting the use of durable medical equipment
- Coordination with pharmacy services and prescribers to maintain current medications
- Coordination with home care agencies for physical or occupational therapy or nursing needs provided at the medical respite
- Facilitation of family and social supports

At the end of life, several other areas of need may arise that call on medical respite staff to work with hospice and other medical and community providers to ensure that needs are met holistically. They include advance care planning, family and social supports, funeral and memorial service plans, spiritual needs, and behavioral health needs that are specific to end of life.

Advance Care Planning and Establishing Advance Directives

Some people may be coming into hospice and end-of-life care having already established their wishes for interventions and supports at the end of life; however, many will not. Only 20% of older adults experiencing homelessness report having expressed their wishes for medical care, and less than 10% have documented those wishes.[6]

Advance care planning is the process of supporting people of any age or stage of health to communicate their personal values, beliefs, goals, and preferences to guide future medical care in a way that is consistent with what is most important to them. This can include planned care at the end of life.

Advance Directives are legal documents that put people’s advance care planning preferences in writing.

Medical respite staff may be called upon to support people in thinking about their wishes for end of life, coordinating and communicating with hospice staff to make those wishes known, and facilitating the formal documentation of those wishes in an advance directive.

The hospice team may facilitate the completion of other forms commonly used at the end of life, including Do Not Attempt Resuscitation (DNAR) orders or Provider Orders for Life-Sustaining Treatment (POLST). It is important to keep these forms on file and readily available for residents who are receiving end-of-life care in medical respite settings.

Resources:

- National Institute on Aging: Advanced Care Planning Conversation Guide
- Example: Provider Orders for Life-Sustaining Treatment Form (PA)
- Example: Do Not Attempt Resuscitation Form (CA)
- SAMHSA Homeless and Housing Resource Center Course on Advanced Care Planning for People Who Use Drugs

Family Reunification, Maintaining Social Connections, and Facilitating Visitors

It is not uncommon for people residing in medical respite programs to work to recover relationships or reconnect with family. When death is expected or imminent, however, these efforts take on a new meaning and importance. Medical respite staff have a role to play in assisting program participants to reconnect with family and friends; these efforts can be supported with guidance from the hospice team.

Staff can help find contact information; help facilitate phone calls, emails, or visits; or support program participants with writing letters to family and friends.

> It is important to note that staff's role is to facilitate communication—not to convince a program participant's family or friends to reconnect with them.

In the event that someone the program participant reaches out to does not want to communicate, staff can then help the participant work through their emotions and disappointment, including offering to support the participant in writing a letter so that they can say what they want to that person. Whether the recipient accepts or reads the letter is up to them.

If the program setup is such that participants can die at the medical respite (as opposed to transferring to a hospital or inpatient hospice), it may be necessary to consider visitor policies for end-of-life participants. Family and friends may want to visit longer, stay with the person, or visit during what would usually be non-visiting hours. Having a policy in place that outlines the number of visitors allowed, lengths of visitation, and how to set up after-hours visiting will help staff coordinate and facilitate visits in an equitable manner.

Memorial and Funeral Planning

One component of end-of-life planning is planning for funeral and cremation or burial needs. Medical respite staff can help determine a program participant's wishes for funeral services and burial or cremation, connect participants to those services, and finalize a plan.

It is often helpful for agencies of all types that work with older adults, PEH, and formerly unhoused individuals, including medical respites, to develop a relationship with a funeral home to help facilitate these conversations and arrangements.

Many states have programs to cover the costs of funeral and burial needs for people with low or fixed income, and funeral homes will often be willing to set up a relationship with service providers. Such a relationship not only provides stability and transparency in terms of process and cost, but also allows funeral home staff to develop relationships with staff and to gain knowledge into the unique needs of their program participants.

Meeting Spiritual Needs

Meeting program participants' religious and spiritual needs is an important part of providing holistic care, and the timely availability of these services can be integral to meeting participants' needs at end of life. Medical respite staff can proactively seek information about their participants' spiritual needs and find out if there are things they can do to meet those needs (e.g., providing them with a particular religious text; connecting them with religious representatives or facilitating a visit; ensuring quiet time or spaces for prayer, meditation, or reflection; or providing access to natural spaces, even through a window). Most hospice teams include a chaplain, and that person will be an important partner in this work.

More information on meeting spiritual needs at the end of life can be found in the section *Preparing for and Responding to Death*.

Meeting Behavioral Health Needs Unique to End of Life

Any time of transition can prompt new or increased behavioral health needs; this is also the case for approaching one's own death and other end-of-life concerns. Behavioral health needs at the end of life may include a need for mental health services, increased contact with behavioral health providers, medication changes, or support for substance use.

Medical respite staff can facilitate the delivery of behavioral health services first through a thorough intake process that asks questions about past and current behavioral health needs, goals for behavioral health at end of life, and anticipated needs. The assessment of need then becomes an ongoing process as staff check in with program participants and help coordinate services.

Medication Management

Introduction

Medications are a critical component of end-of-life care. Medications play an important role in supporting comfort and dignity for the person through managing symptoms related to the end-of-life process, including pain and discomfort, and continuing to manage and treat pre-existing and chronic conditions. In order to best support program participants at end of life in medical respite, programs should use a person-centered approach to care and become familiar with the role and purpose of medications in end of life. This understanding will help programs ensure their program participants have safe and consistent access to needed medications and allow providers and staff to serve as advocates for the program participants when needed.

Importance of a Person-Centered Risk Mitigation Approach to Care

People experiencing homelessness face higher levels of stigma and discrimination than the general population within many health care settings; these biases are often exacerbated if the person has a history of or is currently using drugs or alcohol. The barriers that exist to accessing health care for acute and chronic conditions (such as lack of primary care, preventative screenings, or medications) often contribute to early mortality and the conditions that then require the person to need end-of-life care.

Often, in traditional medical settings, unhoused individuals seeking care have their pain minimized, with providers assuming that their reports of pain and discomfort are exaggerated or that the person is seeking analgesics beyond their actual need. As a result, PEH often do not receive adequate care or pain management, which can have significant consequences.[7] In some cases, people may increase their substance use or rely on street-purchased drugs to alleviate or manage their pain. Mistrust in medical systems as a result of inadequate care leads to people not seeking medical care until a situation is emergent or at a point of crisis and leads to care being provided through emergency departments, even when that is not the best setting to meet the person's needs. When conditions have significantly progressed, the person may then require hospitalization, and without access to supports around advanced care and end-of-life planning, may undergo interventions or procedures they would not prefer (e.g., intubation). In these circumstances, it is incredibly difficult for individuals to advocate for alternative plans of care, including moving into hospice or end-of-life care, vs. continued medical interventions. These individuals may then complete their end-of-life care in the hospital, perhaps separated from their community, instead of being able to die peacefully in a setting of their choice. And finally, without a person-centered approach to care, some individuals do not seek medical care or pain management support at all, resulting in painful and unplanned deaths on the streets or in shelters.

Person-centered risk mitigation is an approach that works to decrease harm and risks to health and well-being while also supporting health goals; it is often applied to substance use but can be applied to any health behavior. Approaching end-of-life care through a person-centered lens can mitigate the substantial and negative impacts of bias, and ensure or increase access to pain management, palliative, and hospice care regardless of a history of substance use, current use, or whether or not they chose to take medications for chronic conditions, including mental health diagnoses. When a person has access to hospice care through medical respite, the medical respite program can minimize some of the barriers (e.g., needing a fixed address to fill certain prescriptions), provide stability to inform medical and advanced care planning, and support the person in accessing needed medications to manage pain and symptoms associated with their condition.

Person-centered risk mitigation aligns with the principles of palliative care, hospice care, and medical respite programs. Person-centered risk mitigation and end-of-life care both promote dignity throughout life, focus on quality of life without judgment, and prioritize the autonomy of the individual. Person-centered risk mitigation principles applied to medication management in hospice care allow providers to build trust with program participants, tailor care to the participant and their needs, and promote safety for the participant at end of life.

Medical respite programs will likely find alignment with hospice providers around the principles of autonomy, dignity, and comfort at the end of life. Medical respite staff may need to be advocates for their program participants with hospice providers to minimize potential bias towards those who have been unhoused or use substances and can also work to address some of the concerns around safety that may be presented by their hospice partners.

The remaining content of this section integrates person-centered practices within medication management for end-of-life care in medical respite, while providing recommendations for programs to ensure overall safety and quality care for their program participants at end of life.

Understanding Medications Prescribed at End of Life

A person may be prescribed medication while in hospice care to address existing health conditions and to manage specific symptoms related to end of life, including physical and behavioral health needs. People will typically continue to be on medications they have been prescribed for chronic and existing medical and mental health conditions. These are not always discontinued when the person enters hospice care, as maintenance of conditions and related symptoms are important through end of life.

Medications prescribed specifically for end of life and hospice care focus on three specific concerns: 1) addressing and alleviating physical suffering and discomfort, 2) addressing psychological symptoms, and 3) addressing existential symptoms related to end of life.

The next section will review the more common symptoms and medications used to treat them, with a goal for providers to become more familiar with these medications and their use. Although the structures of care presented in this guide rely on hospice providers to prescribe and manage a person’s medication, it is important for medical respite program staff to be aware of what kinds of medications their program participants may be prescribed and what they are for. Many medications for pain have stigma attached to them, and staff may be concerned or wary of their use. Understanding that these are a typical part of the hospice process and why they are used is important education for staff to have so that they are able to safely support a person in their prescribed medication regimen.

Although this section will provide a general overview of medications, it is important to note that medications prescribed are individual to the person and their experience, so each person’s regimen and medications will be different as prescribers will respond to each person's symptoms, life history, and experiences.

Addressing Physical Symptoms with Medications

The primary physical symptoms that are often managed at end of life include pain, shortness of breath, and nausea. Often, opioids are the medications used to manage pain and shortness of breath, including morphine, hydromorphone, and fentanyl, and methadone in some cases. These medications may be administered orally (taken by mouth), sublingually (placed under the tongue), or in settings that can support it, intravenously (IV). Additionally, a person may be prescribed medications such as scopolamine or glycopyrrolate to address excess secretions, ease breathing, and reduce the noisiness of a person's respiration. These medications can be helpful for the person, but they also can reduce breathing noises that can be distressing to caregivers, other participants, and staff. For nausea and vomiting, a person may be prescribed medications such as ondansetron, haloperidol, or benzodiazepines. In some cases, a provider may offer palliative sedation, which is used to relieve extreme suffering by making the patient calm, unaware, or unconscious.

Addressing Psychological Symptoms with Medications

Individuals with pre-existing behavioral health conditions will likely continue their medications as part of hospice care. Regardless of history of mental health conditions, individuals may begin to experience agitation, anxiety, or delirium as they approach death. These symptoms may be treated with antipsychotic medications, such as haloperidol, or with benzodiazepines, like midazolam or lorazepam. Agitation and delirium can naturally occur as part of the dying process and can often be managed with the use of medications.

Addressing Existential Symptoms with Medications

As a person enters end-of-life care, they may experience feelings of sadness or anxiety related to this transition. However, in some cases, these may manifest into more significant symptoms, such as depression or clinical anxiety, that require treatment with psychiatric medications. Working with behavioral health providers can help provide the person needed support as they transition into hospice care. The behavioral health providers can also help differentiate what might be part of the typical end-of-life process vs. what might need additional treatment through medications.

Hospice Kits

Most hospice providers provide those enrolled in hospice services with what is known as a hospice kit, usually a small box containing medications meant to address common symptoms that can arise for hospice patients, such as pain, anxiety, excess secretions, diarrhea and constipation, and nausea. Upon admission, hospice staff will provide education on and orientation to using the medications in the box. Usually, people are asked to notify hospice staff when they have had to use a medication from the box. This allows staff not only to make sure the box contains an adequate supply of medications but also to more formally address any new symptoms that need ongoing management.

Considerations for Prescribing Providers

Although most medical respite programs may not be prescribing the end-of-life medications for their participants, they can support hospice and prescribing providers in addressing end-of-life needs through a person-centered lens. Additionally, the medical respite program may be prescribing or managing their participants' other medications, and care coordination and communication about health status and medications is critical. These recommendations can be shared with any hospice provider a medical respite program is partnering with.

Recommended practices for prescribing medications in end-of-life care for PEH include:

- Using a person-centered, compassionate approach.
    - Providers should get to know the program participant and their goals for end-of-life, their experiences in the health care system, and learn about and be mindful of the participant's current or past substance use.
    - This information should be gained in non-judgmental, stigma-free conversations.
    - The focus of care at end of life should primarily be focused on treating the present symptoms.
- Hospice providers and medical respite programs may want to partner with person-centered programs that focus on substance use to support the person and minimize risks, such as providing the program participant with naloxone and overdose education.
- Modify how medications are prescribed to increase safety and reduce risk, such as prescribing long-acting medications to reduce frequency of dosing, or prescribing medications to be picked up or delivered more frequently (e.g., weekly) to reduce the amount of medication a program participant has on them.
- Be proactive in educating about and managing potential side effects to minimize the program participant experiencing discomfort or waiting for additional visits for relief from side effects.
- Ensure that medication instructions can be implemented and followed in the person's current context.
    - In medical respite settings, the staff will rely on the hospice providers to administer medications or complete activities, such as changing pain patches. Prescriptions and dosing should match the availability and support of the hospice providers and program parameters.

Partnering with Hospice and Medical Providers for Medication Management

When a medical respite program provides end-of-life care through partnerships with a hospice program, they will not be prescribing the person's end-of-life or palliative medications. However, medical respite programs maintain important roles in supporting the program participant with their medication management, including: safe storage of medications, support in following medication regimens and providing space for medication administration, support in accessing medications from pharmacies, supporting the program participant in communicating or advocating for their needs (or in some cases communicating and advocating on behalf of the participant), monitoring changes in status or symptoms, and educating partners on person-centered risk mitigation strategies.

Within the structure of providing end-of-life care in this guide, program staff would likely not administer medications to the program participant but would partner with hospice staff regarding medication administration. For some programs, the point at which a program participant is no longer able to administer their own medications is the indicator that they would need to transition into a different level of care or hospice program.

Recommendations for Medical Respite Program Staff in Supporting Medication Management

Medical respite program staff play a critical role in supporting their program participants' ability to take and manage their medications. The following recommendations will help program staff to play this supportive role:

- Communicate with the hospice providers when the program participant is no longer able to or is approaching being unable to self-administer their own medications.
    - Programs at this point may:
        - Arrange a transfer to a higher level of care.
        - Coordinate with hospice so that the hospice providers can administer all medications.
        - Allow medication administration by qualified medical respite program staff in alignment with the medical respite program's policies and procedures.
- Become educated about and familiar with medications prescribed by hospice providers for end-of-life care.
    - This guide can serve as an introduction to build familiarity with medications prescribed under a person-centered lens.
    - Hospice prescribing providers and nursing staff can provide training and education to medical respite program staff.
        - The NHCHC Substance Use Guidelines can be a helpful tool for education.
    - Educate staff to monitor for signs of overdose and on procedures for responding to a potential overdose.
- Use collaborative care and lines of communication with the hospice providers to address any concerns about medication.
    - Ask the hospice staff to provide education about medications and dosing to help the program participant to follow their regimen.

    - Ensure patient education materials are in plain language and understandable to the program participant.
    - Learn specific recommendations around the storage of medication from hospice staff.
    - Report or share if the program participant is appearing to have difficulty with their medications or using the medication storage mechanism.
- Support the program participant in communicating to or advocating with hospice providers to address pain or other symptoms that the participant is experiencing or that the current medications are not adequately addressing.
- Attend appointments and be present during bedside visits with the program participant and their hospice provider to help understand, communicate, and provide education to the participant as needed and as requested by the participant.
- Educate the program participant about how to:
    - Contact their hospice providers to ask questions or report concerns and symptoms about their medications in coordination with program staff.
    - Reduce risk of, monitor for, and respond to potential overdose.
- Monitor the program participant's symptoms and status as part of routine wellness checks:
    - Contact hospice providers with any concerns or change in status.
        - In some cases, this may indicate a need to transfer from the program into another facility.
- Support the program participant in self-advocacy and autonomy in their decision-making as much as possible and demonstrate this through supporting their decisions regarding their medications.
- Provide strategies or methods for the program participant to follow their medication regimen, such as:
    - Call in or picking up refills on time.
    - Set reminders or alarms to take medications.
    - Use a pill box.
    - Set up a system to track appointments and upcoming visits from providers.

Medication Storage

General recommendations regarding medication storage and management in medical respite can be found in the resource Medication Support and Medical Respite Care: A Guide for Programs from NIMRC.

This section will apply these general recommendations and practices to supporting end-of-life care.

All medical respite programs should offer a mechanism to securely store medications, and program participants should be able to access medications at all times to manage their health needs. These practices also apply to program participants receiving hospice and end-of-life care.

As described earlier in the document, some of the medications prescribed for end-of-life symptom management are controlled substances and can present safety concerns, especially when other program participants of the program may currently be using substances or if the program is concerned about risk for overdose. However, the principles for providing end-of-life care should remain the same as other aspects of this care in that the process for storing medications should be person-centered and allow the participant access to their medications when and as needed.

Programs may pursue two pathways for medication storage: self-storage and program storage.

The program can encourage the program participant to talk with their prescribing providers about their medication regimen and provide education to reduce overdose risk, but at the end of the day, staff need to remember that program participants are people living within the community who have the ability to make their own choices around how and when they take medications. Providers must recognize that the program participant has the best understanding of their safety needs and that the provider's job is to listen and respect their understanding of the program participant's safety. Developing a trusting relationship and providing resources can allow opportunities for discussion, education, and encouragement in a way that is respectful to the program participant.

> Regardless of how medications are stored, programs need to ensure that they are respecting program participants' choice in autonomy around medications.

1) Self-Storage of Medications

Programs may opt to have the **program participant self-store all of their medications** in their room and an individual lock box.

Supplies for safe storage of medications by the program participant include:

- Individual lock boxes (even if the person has a private, locked room)
- Tamper-proof containers
- Individual storage boxes or lockers

Additionally, especially for those in more congregate settings, program participants should have access to a private room or place to administer or take their own medications, so that the prescribed medications (or method of administration) are not viewable to others.

Staff protocols and procedures should include that:

- Staff do not handle or administer the program participants' medications.
- Staff have contact information, including on-call and emergency lines, to reach out to hospice providers for immediate concerns regarding medications and administering medications.
- Staff should support the program participant in safe storage of medications, including:

    - Educating program participants to not share lock box codes, keys, or information to anyone except hospice providers.
    - Communicating to hospice providers if the program participant is having difficulty with using storage equipment (e.g., remembering codes or manipulating the dial or handle).
    - Ensuring the program participant knows where private spaces are available to administer medications.

Practices, policies, and procedures for medication storage should align with the general strategies used by medical respite program staff to provide support for the program participant with their medications.

2) Program Storage of Medications

In order for medical respite programs to store medications on behalf of their program participants, the program will first need to contact their State Board of Pharmacy for state regulations and guidelines for medication storage, including for controlled substances (which often have more extensive criteria).

- Programs will need to develop their storage space based on their local State Board of Pharmacy's recommendations, which often include guidelines for temperature control, locked access, etc.
- Programs will need to develop explicit policies and procedures that reflect the State Board of Pharmacy's guidance and should also include:
    - Designating which staff have access to medications and are able to dispense medications to program participants.
        - The Board of Pharmacy may identify that licensing is required for staff to distribute medications to program participants, such as an LPN, RN, etc.
        - Staff that do not have a clinical license may not provide any medication education or guidance on taking medications.
        - All staff should be able to support the program participant in accessing hospice providers who provide assistance and clarification with medication dosing and instructions.
    - Ensuring that all program participants have 24/7 access to their medications and that each shift includes staff who are able to access and dispense medications from the storage area.
    - Processes for document medication dispensing, such as:
        - Sign-out sheets that confirm who accessed the medication storage area, what was accessed and dispensed, and the program participant's receipt of the medication (via signature).
        - Documentation in the electronic medical record system or other internal electronic reports.

    - Policies to address program participant's concerns that medications are missing or have been tampered with and procedures for investigating claims with staff.
- Programs may opt to include additional features in their storage areas, such as security cameras to support the safety of their program participants and staff when handling medications.
- Programs should offer the program participant choice in whether or not they would like to keep their medications with them (and offer locked storage in the participant's room or bed if they decline to have the program hold their medications).
- Program participants should have access to a private room or place to administer or take their own medications, so that the prescribed medications (or method of administration) are not viewable to others.

Conclusion

Medication management is a vital part of the end-of-life care process and should be implemented from a person-centered perspective to ensure dignity, autonomy, and comfort of the person. Programs have a critical role in supporting the program participant in being able to safely store and take their prescribed medications and partnering with hospice providers to ensure medications are meeting their participants' needs.

Facility Considerations

Introduction

A program's physical space contributes significantly to a program participant's comfort and sense of security. Creating a healing-centered environment in medical respite care programs is critical for all participants within the program.[8, 9] Creating choice and safety and promoting health and well-being ensure that the physical space of medical respite programs are person-focused and healing-centered environments. These approaches facilitate program participants' engagement with the space and their preferred routines. In the context of end-of-life care, promotion of health and well-being is less focused on recovery and returning to community and more focused on maintaining comfort and connection to others while approaching death.

Additionally, key features for end-of-life spaces are those that facilitate social interaction, positive distractions, privacy and control, personalization and a home-like environment, and an ambient setting.[10] These features can be applied within the medical respite program that provides end-of-life care as part of a person-centered environment.

General Recommendations for the Layout of the Program

The general layout of the medical respite space can help facilitate a supportive environment for those receiving hospice care. Some of these strategies may be more applicable for medical respite programs that are redesigning or building a new space, as they will have more control over the structure of their building. However, when creating or designating specific spaces for those in hospice care, programs may be able to consider these recommendations:

- For programs that will support the person through the end of life, individual rooms are recommended.
- For programs who support program participants in hospice but transition the participant when they are near end of life, semi-private spaces may be used (see the next section regarding recommendations for sleeping spaces and privacy).
- All program participants in hospice care should be placed near bathrooms or have private bathrooms.
- All hospice rooms should be accessible to central areas of the program and ideally visible to program staff.
    - Program participants and caregivers who have engaged with hospice care have shared that they do not want to feel "shoved away" from others or forgotten by staff and other participants.

Sleeping Space

The sleeping and personal space is where a program participant may spend the majority of their time at the end of life, especially very near to the end of life. Recommendations for sleeping spaces to provide end-of-life care include:

- Private rooms
- Semiprivate spaces for near the end of life or before a participant transitions to a hospice facility or higher level of care
    - Some participants in hospice care prefer a shared space to avoid loneliness, but others (both those who are in hospice or not) also do not want to be near or to hear medical interventions when someone is actively dying.
    - Providing choice regarding shared or single rooms is ideal when appropriate and feasible.
    - For programs that only have semiprivate or congregate spaces, transition to a hospice facility or a higher level of care is indicated when the program participant's medical status or interventions are frequent, potentially disruptive to others, or the participant does not feel like they have privacy when receiving medical or hospice care.
- Private space for medication administration and personal, locked medication storage (see medication storage section for more recommendations)
- Space for caregivers, visitors, volunteers, or other supports to comfortably sit and visit the person
    - This may include recliners to support rest if the program participant is being observed by others 24/7 or has requested a support person to be with them.
- Space and ability to use comfort items and DME, such as:
    - Hospital beds
    - Comfortable seating (e.g., recliners, moveable chairs)
    - Place to store extra pillows and blankets for propping and positioning
    - Outlets to plug in items, such as oxygen tanks or heating pads
    - Space to store DME and other medical equipment so that it is not always visible to the program participant.
- Space for interactions with other health care providers, including medical respite program staff and hospice staff, to converse privately with the program participant or to provide medical care.
- Creation of a home-like and comfortable environment
    - Recommendations identify that making the space feel less medical is better, which may require a place to store medical equipment so that it's not front and center of the room.
- Space for personal items to be stored or displayed

- Ability to individualize their room or space, including:
    - Displaying artwork (simple, not busy) or art of the person's choice
    - Adding small comfort items, such as specific pillows, lamps, or blankets preferred by the person
- Ability to control the temperature of the room
    - When possible, offering individual control of thermostat for each room
    - Providing items that could promote an individualized comfortable environment (e.g., fans, blankets)
- Adequate lighting
    - Providing natural light as much as possible
    - Reducing the glare of overhead lighting
    - Including night-lights or low lighting to promote sleep but also ensure safety with movement at night

ADA[*]-Accessible Spaces and Activities of Daily Living (ADL) Support

People experiencing homelessness in general have a higher need for mobility aids and are more likely to experience functional changes at younger ages. A need for ADA-compliant and accessible spaces for mobility needs also increase during end of life both due to conditions and increasing fatigue.[11] Individuals in end-of-life care may also need DME to increase comfort and to prevent adverse events such as falls.

ADL Supports

- Bathrooms should have built-in accessible features or have space to add DME, including:
    - Shower chairs and benches. Shower benches with sliding seats are useful once the program participant requires caregiver assistance to transfer.
    - Grab bars
    - Non-slip treads and surfaces
    - Raised toilet seats or handles (e.g., grab bars) around the toilet
- Bathrooms should have adequate space for caregivers to be able to comfortably support the program participant during ADLs.
- Bathrooms should ensure privacy, especially if ADLs are supported by the hospice or caregiver agency.

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[*] ADA refers to the [Americans with Disabilities Act]

    - The program participant may need to complete ADLs at a time when others commonly do not use the shower to help ensure more privacy when being supported by staff or a caregiver or when they have able to have more time.
- Additional equipment that is not typically used by medical respite programs but supports end-of-life care, including:
    - Lift and transfer equipment in the person's room (used to transfer from bed to sitting in chairs; wheelchairs)
    - Pressure-relieving mattresses
    - Use of bedside commodes or urinals

An indicator for programs to transition the program participant to a higher level of care or hospice program may be when a participant is no longer able to safely navigate the medical respite program by themselves, when they are unable to complete ADLs, or they require more equipment for ADLs and assistance than the program has available (e.g., use of lifts for transfers).

Cognition and Confusion

Cognition can be affected or can decrease when a person is approaching the end of life. There is not one specific trajectory for cognitive changes, but people may experience changes in memory, concentration, and language, and may experience confusion about time and place.[12] The causes of cognitive changes can be related to the person's medical conditions or be a result of treatments or medications. Cognitive capabilities may fluctuate. To ensure spaces are safe or accessible for people with cognitive changes or confusion, the following actions are recommended:

- Use clear signage throughout the facility that indicates the name and purpose of rooms or that provides directions to main areas of the program (such as dining spaces, main community rooms, and bathrooms).
- Use clear signage to indicate spaces that program participants should not enter.
- Use clear signage, name tags, or familiar items on doors or beds, so program participants can easily find their own rooms or beds.
- Place program participants with more cognitive impairment or confusion in beds or rooms closer to staff, so they are more easily able to find help from staff.
    - This may be near staff offices, desks, or other spaces where staff are readily available.
- For program participants at risk of wandering or leaving the facility, place them away from exits or doors, or so that they would need to pass staff (including security or front desk staff) to exit, allowing the opportunity for redirection.

If the program participant is experiencing continued delirium, delirium that can't be reduced, or has wandering or safety risks, this may be an indicator for some programs to transition the participant to a higher level of care or hospice facility that can provide more security.

Community Spaces That Can Be Accessed by All Participants

- Offer community areas, such as living rooms, outside spaces, and dining areas, that are accessible to everyone, including those with mobility devices.
- Provide different types and styles of seating and furniture to help program participants sit comfortably in communal spaces.
- Use clear signage so that these spaces are accessible and easy to find by participants.

(See additional section on community spaces regarding design and structure)

Medication Storage and Access

Safe medication storage and access is a key component for all medical respite programs (Models of Medical Respite Care, Standards for Medical Respite Care). Full recommendations for medication storage in medical respite care programs can be found in NIMRC's Medication Support and Medical Respite Care: A Guide for Programs.

As identified in the section on prescribing medications, medications for program participants in hospice care will often include as needed (i.e., PRN) medications and prescriptions for controlled substances, including at high doses. The physical space of the program should support the program participant's prescribed medication regimen and support the safety of the participant, the staff, and other program participants.

If medications are completely managed and administered by the program participant and an outside hospice provider, medical respite programs should provide the following:

- Individualized lock boxes in the program participant's room to store medications. This may need to include a locked refrigerator.
    - The hospice program may be able to "prescribe" locked medication boxes.
- Collaboration with the hospice program to support the program participant if they have memory concerns that would impact their ability to remember a combination or other code for their medication storage.
- Education to the program participant on the importance of keeping medications locked and not sharing their key or combination with anyone except hospice staff.

If medication storage is provided by the medical respite program, the following listed guidance should be followed:

- Adherence to state regulations for the storage of medications, including any controlled substances. This typically requires that medications are stored behind two locked doors with only select staff having access to this space.
- A sign-out form completed every time medication is taken out of storage and administered or given to the person. This would include name of the staff, date, amount of medication distributed to the person, amount of medication left, and date and time medication is put back into storage.

- Staff with access to the medication storage space should be available 24/7 to ensure the program participant can access their medications at any point in time, especially with pain and as-needed medications.
- See the section on *Medication Management* for further details on medication storage.

Community Spaces

Many individuals at end of life desire connection and socialization with others. Being able to engage in activities can be a strategy to support pain management or provide needed distraction from physical conditions or concerns about approaching the end of life. Program participants engaged in hospice care should not be completely segregated from others and should have the option and support to participate in activities or leave their rooms as needed or desired.

Ways to create a supportive community space include:

- Spaces to socialize, be with others, and engage in meaningful or community activities
- Access to:
    - Art, both to view and engage in
    - Music, both to listen to or participate in
    - Nature (via accessible outside areas such as gardens or patios, windows, or hanging bird feeders) or indoor nature scenes
    - Social activities, such as games, movie nights, etc.
- Pleasant scents and efforts to reduce medical odors
- Colors that match the intended activity of the room. There is mixed evidence on ideal colors for hospice care; however, brighter and energizing colors in common areas and calmer colors in rooms and sleeping spaces (e.g., blues and greens are identified frequently as soothing, open, and peaceful) are frequently recommended.
- Peaceful sounds such as white noise or soothing music.
- Space for visitors, especially multiple visitors, if individual rooms do dont have enough space for this (or the person does not have individual space)
- Spaces for memorial activities:
    - Memorial events or services
    - Space to honor those who have passed, such as pictures, memory walls, etc.
    - Physical recognition that someone has passed, such as placing butterflies or birds on doors of private rooms, etc.

Recommended Resources:

To learn more about creating supportive and healing-centered environments in medical respite care, please review these resources:

- Person-Centered Environment in Medical Respite Care
- Person-Centered Environment Checklist
- Creating Healing Spaces: Designing with Dignity in Medical Respite Care Virtual Symposium

Program Operations

Medical respite programs interested in expanding services to support program participants at the end of life can build upon best practices identified in foundational NIMRC resources when making modifications to program operations. These resources include:

- Standards for Medical Respite Care Programs
- Guiding Principles of Medical Respite Care
- Models of Medical Respite Care
- The Defining Characteristics of Medical Respite Care

Communication Procedures

Medical respite programs will need to establish formal communication procedures, if they are not already in place, including the availability of call lines. The complexity of program participants' health increases when providing end-of-life care, and these call lines provide additional support to staff both outside of normal business hours and in emergency situations. This is especially important, as a program participant's condition could deteriorate overnight when staffing may be limited. Programs should consider designating an overnight, on-call administrator from within the program staff and identifying overnight support from the hospice agency. Medical staff should provide clear instructions for after-hours non-medical staff, including when to call the hospice agency overnight vs. when to call a program administrator on duty with questions or concerns.

In addition to emergencies, a clear process for communicating routine updates on program participants' health will need to be identified, along with the ways that staff can differentiate between situations that need medical action (i.e., intervention) versus supportive care actions. Programs should also consider establishing a workflow for communicating updates from overnight staff to business hours staff (e.g., a log available online or at the desk, shift notes, morning team huddles, etc.).

To address this, programs can consider collaborating with the hospice agency to create a binder that is kept at the nursing station (or administrative desk) for anyone to access. It can include program participants' rights forms, important phone numbers (including an after-hours support number), and established emergency procedures.

If the program plans to transition a program participant to a more supportive placement near the end of life, consider the following when developing communication procedures:

- How will updates in the participant's condition be shared between the medical respite program, hospice provider, and discharge placement (if not discharging to the current hospice provider)?
- How will discharge plans be shared among staff and other program participants?
  - Will there be a formal opportunity for others to visit with the program participant before discharge?
  - If notifying other residents of discharge, ensure HIPAA compliance is maintained and the participant agrees to the sharing of information.

- How will coordination and communication with the discharge location be managed?
    - What will the program manage vs. what will the hospice manage?
- How will the program participant's family or loved ones be included in the discharge process (unless the participant states otherwise)?
    - How will they be notified of the plan to discharge?
- Will follow-up communication occur with the program participant's discharge location?

Programs supporting program participants until the end of life will need to consider similar procedures, specifically:

- How will updates in the program participant's condition be shared between the medical respite program staff, other participants in the program, and the hospice provider?
- How will staff and other participants be notified of a participant's decline in health and eventual passing?
    - Does the facility have the ability to clear the space (e.g., close off the dorm, remove other participants from hallways or entryways) when a participant passes and is removed from the building?
- How can program participants and staff be immediately supported after a passing?
    - Consider identifying a leadership staff member to arrive on-site for after-hours passings.
- How will family or loved ones be notified of a program participant's decline in health and passing?
    - Will the hospice agency or the program notify family and/or loved ones? Consider including language in a memorandum of understanding (MOU) with the hospice agency regarding procedures.
- Are there community partners that need to be contacted (e.g., morgue, cremation or burial services, outside providers, etc.)?
- Will the program participant's passing be publicly communicated (e.g., a memorial social media post or obituary)?
    - If providing public notification, ensure media releases are signed upon admission by the program participant, power of attorney, or next of kin.
- Will an area be set up as a memorial or remembrance for the program participant who has passed? An example can be as simple as leaving a bouquet of flowers on the participant's bed.
- How will program participants' belongings be managed?
    - Consider identifying a procedure for removal, a place for storage, and establishing time limits on pick-up or delivery to family or next of kin.
    - Consider management of belongings if there is no one designated to receive them (e.g., donation room on-site, donation to other community organization, etc.).

Programs can also consider holding a community meeting with other participants and staff to discuss when a participant is nearing death. Regardless of which path is chosen to notify others of discharge and/or onset of death, these procedures should be clearly outlined and shared with every participant at admission to the medical respite program, with an option given to keep their health status private. Participants should also have an opportunity to opt out of updates on other community members if they desire. Procedures should also be established to allow participants to decide if they want to limit information sharing to only the necessary staff providing direct care, compared to an all-staff memo.

Visitation Policies

Visitation policies for program participants may also need to be adjusted for participants receiving hospice care. If desired, staff should make attempts to reconnect these participants with family or loved ones, which can include using volunteers or an outside partner, such as an attorney, to assist with finding family. Traditional program visiting hours may need to become more flexible to ensure there is ample time to receive visitors in person and to accommodate fluctuations in health status. For family or loved ones who are not local, attempts can be made to offer an opportunity to spend time together virtually or over the phone. Programs can also utilize tablets or laptops and offer a private space to facilitate video calls.

Programs can also consider creating a visitation guideline document that visitors sign upon arrival. This document may not be necessary for individuals spending an hour or two on-site, but if the program allows overnight visitation, having established procedures can mitigate conflict or difficulties. Staff will also need to be trained in how to manage disruptive visitors and conflict resolution to support all participants and guests on-site.

It’s also important to note that these visits may be very emotional, and the program participants or visitors may need additional support and health education regarding their illness and prognosis. Staff may need to assist participants with logistical arrangements and emotional support during reconnections. There may also be occasions when the program participant will not have any visitors or individuals to visit or reconnect with. In this instance, the medical respite program should focus on building a support system among staff, other residents, and volunteers, including the No One Dies Alone Program previously referenced. Programs can also consider a partnership with, or employment of, a chaplain who is available upon request or need.

Space for visits should also be considered. In congregate facilities, more private spaces may be identified for family visits (e.g., social work offices, outdoor courtyards, etc.). Staff can facilitate these meetings and coordinate schedules. Program participants with private or semi-private spaces (shared with one to two other individuals) may choose to hold visits within their living space. Programs should offer participants choices and options as much as the program’s logistics allow.

Program Environment and Recreation

When program participants choose to enter hospice care and a medical respite program, they will likely experience a dramatic shift in their living environment, community, and daily activities. Programs should:

- Address age disparities
- Facilitate connection to community
- Provide recreational opportunities

Age considerations are especially important during program development, as the most glaring discrepancies in mortality ratios are seen in the younger and middle-aged groups from 18–34 and 35–54 years of age. People experiencing homelessness have a 3.5 times higher mortality rate than those who are housed.[13] This requires a shift in the perspective that hospice care is a support for older adults.

If the medical respite program is not currently located near community connections that the program participant already has, consider how to provide opportunities for the participant to access that community and offer occasions for them to reconnect at the medical respite program. This can include previously mentioned visitation hours, hosting social events and gatherings that allow outside visitors, or transportation to community locations or events that allow program participants to keep company with their established support systems. There may also be community programs available, such as adult day programs, that can be utilized for social activity options.

As much as program participants will need clinical and emotional care, they will also need recreation and an environment that contributes to their overall happiness and feeling of community.[14] To meet this need, programs should intentionally create opportunities for medical respite and hospice participants to engage in recreational activities. These activities can be offered on-site or include outings to parks, movies, and events in the community. Recreational activities do not have to be fully decided before the program begins supporting program participants in end-of-life care. Consider the following actionable steps when developing recreational programming.

Examples of evidence-based recreational practices and interventions, including suggestions by diagnosis (e.g., terminal cancer), can be found on Temple University's RT's Wise Owls database. Figure 4 offers suggestions for beginning to plan recreational activities for programs.

Designing Recreational Programming

- Survey participants on their interests
- Use survey responses to guide program design and development
- Consider peer-led activities
- Set regular and ongoing time for activities
- Provide a variety of recreation options
- Encourage participant choice
- Provide a positive environment for engagement

FIGURE 4: SUGGESTED RECREATIONAL ACTIVITIES FOR MEDICAL RESPITE AND END-OF-LIFE PROGRAMS

- Cooking or painting classes
- Yoga & Meditation
- Gardening
- Group trivia or game night
- Poetry writing and readings
- Music therapy and/or Karaoke
- Movies or video games
- Animal therapy

Program Operations for Different Health Outcomes

Program operations relating to the health outcomes of program participants overlap, regardless of whether the participant will be discharged to a higher level of care or remain in medical respite for the duration of life. Both pathways for providing care will need to establish procedures for how other participants and staff will be notified when a program participant is nearing the end of life while also respecting the participant's wishes and privacy. In some programs, participants may move rooms to be closer to administrative or nursing desks, symbolizing that closer proximity means more support is needed. Other programs place a marker on the outside of the door so that people passing by or entering are aware of the participant's current health status.

In some instances, a program participant with a terminal diagnosis may actually improve once they are sheltered and receiving stable clinical interventions. Programs should create a process in the event a participant has a positive health outcome. This includes how they will transition the participant to supportive, stable housing and a plan for them to continue receiving medical care. Alternatively, a participant may be in hospice for an extended period of time before needing a higher level of care or passing away. This increased length of stay can impact bed availability, overall census, cost, and needed staffing levels. Preparing for various outcomes requires identifying what supports need to be in place within the program and identifying a response to each outcome before accepting the first end-of-life care program participant.

Program Operations for Staff and Other Program Participants

When determining whether your medical respite program can expand to provide end-of-life care, the needs of the participants should be at the forefront of decision-making. Programs should be accessible, low-barrier, and avoid excluding particular groups when possible. Participants will need to agree to receive hospice care and enter the program. From admission, they should have as much input on decision-making as possible. The hospice provider may offer health education, complete advanced directives, and help the program participant prepare for death, but the medical respite program should also be knowledgeable in this area to fill any gaps.

However, palliative care and hospice patients are sometimes not capable of engaging in the types of interactions required to make end-of-life choices independently, and the influence of others is crucial both physically and psychologically.[15] Because of this, program participants may need support and education about what to expect after receiving a terminal prognosis, and staff should anticipate helping them come to terms with the end of life and deciding how they want their care to be provided. Often, this level of assistance comes from family members, a support system that someone who is unhoused may not have.[16] Program staff can become guides and advocates during end-of-life decisions when family is unavailable, which will require different types of staff training, programmatic offerings, and community partnerships.

One major operational change will be integrating hospice and palliative care providers as a partner with the medical respite program. Staff may have to yield decision-making regarding the care plan that is established by the hospice provider and fulfill more of an advocacy role for the participant. This can also require a change in the type of staff, quantity, the hours they are available, and other duties (e.g., more case management staff may be needed and may need to work outside of traditional business hours).

Adjusting operations to support program participants receiving end-of-life care will also require the evolution of the perspective that medical respite is a place for healing, recuperation, and discharge to housing. Staff and other participants may have difficulty adopting this mindset, and may need support, additional training, and education.

When end-of-life care is offered, the program participant has access to a place to die with dignity and to receive the pain management and supportive care they might not have been able to receive if they were unsheltered or had spent their remaining days in the hospital. This does not discredit the emotional toll that offering end-of-life care can have on other participants and staff but instead highlights a need to reframe the idea of how medical respite can be defined and what role it can play in the homeless healthcare continuum.

Programs should offer grief-specific support to both participants and staff, which may not currently be available in medical respite spaces. This includes educating staff on managing their personal grief and offering them guidance on supporting the participant receiving hospice care and the other participants in the medical respite program. These services can be provided by counselors or trained staff employed by the program, external partnerships, peer support groups, or other professionals. Grief support offered to participants should be tailored to the participant receiving hospice care (e.g., how to come to terms with death) and to other participants in the medical respite (e.g., how to be in community with someone receiving end-of-life care).

Staff grief support should assist with caring for someone nearing the end of life and assist staff with processing death. Consider offering staff debriefs after each passing and offer a remembrance of program participants on an annual or biannual basis. Staff can learn tools to educate participants on the importance of building a supportive, welcoming community, which can increase the overall well-being of all participants and provide an additional avenue of support in challenging situations.

Preparing for and Responding to Death

Introduction

For most people who are dying [in hospice care], the body's normal systems start to operate more slowly. For some people, the dying process may last weeks. For others, it may last a few days or hours. It is helpful for caregivers to know what to expect and how to support people through the dying process.

While the process of death cannot be neatly divided into stages, certain common signs and symptoms you may notice at different time include:

Early stage. The person eats and drinks less, sleeps more, and may seem to withdraw.

Middle stage. The person may look pale and have cold hands and feet. They could have changes in their vital signs and bathroom patterns.

Late stage. The person could become restless, confused, or unconscious. Their breathing may become irregular and may make a rattling sound.

In this section, we will go over the practical aspects of preparing for death as well as details of how program participants may present during each of these stages.

*Appendix A p*rovides an overview of the timeline for end of life.

Practical Aspects of Preparing for Death

As people are able, it is important and helpful to sit with them to identify any end-of-life wishes they may have. This section provides prompts, suggestions, and ideas.

- What is it you need to feel physically comfortable, especially when you become chair- or bed-bound? Examples: a favorite item of clothing, cozy clothes, socks, blankets, music playlists, ambient comfort, such as candles (they can be battery operated if necessary), essential oils, dim lights, no TV or TV on a specific station, and so on.
- How would you like to be remembered or how you would like to remember others?
- What would you like us to do with your possessions?
- What do you need to feel less anxious about your passing?
- Would speaking to a chaplain or other spiritual person feel supportive to you?
- What would you like to have done with your body when you die (cremation, burial, donation to science, etc.)?
- Work with the team, including outside hospice providers, to complete an advance medical directive.

Preparing for the Physiological Changes of Active Dying

Early Stage

Detachment or Withdrawal: A person may seem unresponsive, withdrawn, or in a comatose-like state. This withdrawal is often characterized by a sense of detachment as the person begins to disengage from their surroundings and to prepare for the end-of-life transition. It may be a way for the person to conserve energy and focus inward. It is a typical end-of-life symptom.

Supportive Actions: Offer gentle interventions to provide comfort and connection. Despite appearing unresponsive, know that their hearing remains. It is important to continue speaking to them in a normal voice and identifying yourself. Hold their hand. Say what you need to say. This helps them let go.

Decreased Intake or Refusal of Food and Liquids: A decrease in appetite and thirst is a common occurrence as the body's systems begin to shut down in preparation for the dying process. The body naturally conserves energy as it approaches the end of life. When this happens it is important not to force them to eat or drink, as problems with swallowing can cause choking or coughing with any attempt to ingest medication, food, or fluids. This is why many hospice medications are given as drops under the tongue or as transdermal patches.

Supportive Actions: Do not force people to eat or drink if they don't want to. Small ice chips or frozen juice chips could be refreshing and provide hydration without requiring significant effort, but these should only be given if the person is expressing interest. Apply lip balm to prevent chapped lips because of decreased fluid intake. Use a damp sponge to wet their mouth if it becomes dry and uncomfortable. If medication is needed, it should be given via quick dissolve tabs or liquid that can be placed under the tongue or given through the skin or by injection. Once a person stops eating completely, it can be helpful to give a laxative suppository to help clear out their bowls and decrease discomfort from constipation if this is an issue.

Increased Sleeping: A dying person may withdraw, bit by bit, from life—a process described as "detaching."

Supportive Actions: Acknowledge that sleeping more frequently is normal. Keep the environment as calm as possible by dimming bright lights or playing music that is soothing to the person. Gentle turning and repositioning can ease muscle stiffness and reduce pressure injuries to the skin. If the person expresses discomfort or has visible signs of pain (such as grimacing) with movement, time repositioning around the person's pain management schedule or talk to the medical respite or hospice team about adding pain medication as needed. Some people will want someone with them, and others may not. Based on the person's preference, sitting quietly with them holding their hand and speaking to them in a normal voice is something volunteers can offer. Despite sleeping, the person can likely hear everything you say.

Middle Stage

Incontinence: This involves the loss of control over urinary or bowel functions. This is a common end-of-life change that can occur during the process of passing on but can compromise the person's comfort and dignity.

Supportive Actions: Keep the person clean and comfortable by regularly changing soiled clothing and bedding, using protective pads or undergarments, and ensuring proper hygiene to prevent skin irritation or infection. If the medical or hospice team suspects urine is being retained, an indwelling catheter may be recommended to drain urine from the bladder. It will help to protect the person's skin, ease pain and pressure from urinary retention, and minimize the need to turn or reposition for diaper or pad changes.

Body Temperature Changes: Some people will experience a noticeable decrease in the body temperature of a person approaching death. This can feel like cool extremities, such as the hands, arms, feet, and legs. Also, the color of the skin may change and become blotchy and pale, purplish or grey depending on their skin tone, especially on the knees, feet, buttocks, ears, and hands. The cooling of the body is a natural part of the active dying process and occurs as the body's circulation slows down and vital organs begin to shut down. Others may develop a mild fever; their torso and face may appear flushed and feel warmer.

Supportive Actions: Keep the person comfortable. If they are experiencing coolness, apply warm soft blankets and keep the room temperature warm and cozy as able. Avoid using a heating pad to warm hands or feet; thin, fragile skin burns easily. If they are feeling warm, place a lukewarm washcloth on their forehead to provide some relief.

Late Stage

Confusion: People may experience moments of confusion during which they may not recognize where they are, know familiar people, or understand what's going on within or around them. This symptom can cause feelings of fear, frustration, and anxiety for the person.

Supportive Actions: Identify yourself by name before you speak. Speak normally, clearly, and truthfully. Explain routine activities in a calm and reassuring manner such as, "It's time to take your medicine now" with reasoning like, "So you won't start to hurt." Create a familiar and soothing environment, such as playing familiar music or displaying personal mementos, to help ground the person and reduce confusion.

Changes in Breathing: Breathing patterns before death commonly change. This symptom involves changes in how frequently the person takes a breath as the body approaches the final stages of life. Changes may also include Cheyne–Stokes respiration, or shallow breaths with periods of no breathing for a few seconds to a minute, as well as rapid, shallow panting. People who experience Cheyne–Stokes respiration will take several breaths followed by a long pause before regular breathing resumes. These cycles of breathing will become increasingly deeper. These patterns are common and indicate a decrease in circulation as the body shuts down.

Supportive Actions: Elevating the person's head or turning them on their side may bring comfort and ease breathing. Holding their hand and speaking to them gently can offer reassurance and emotional support. The hospice team can provide information on how to use hospice medications to manage respiratory changes and support comfort.

Restlessness: Restlessness can look like repetitive motions, such as pulling at the bed linen or clothing. This can be attributed, in part, to a decrease in oxygen levels and other physiological changes that occur as the body approaches death.

Terminal Restlessness: Physiological changes near the end of life causing discomfort, which can manifest as agitation. It manifests as incongruent behaviors appearing suddenly. This can include wandering attention, aimlessness, and outbursts of emotion and aggression. There's no set type of terminal restlessness; this can make it difficult to predict how a person experiencing symptoms such as terminal agitation may act. It is often different than how you would expect someone in hospice care to act.

Supportive Actions: Do not interfere with these movements or try to restrain them, as this can increase their agitation and distress. Instead, speak in a quiet and natural manner, offering gentle reassurance. Provide comforting touch, such as lightly massaging their forehead. Engaging them in calming activities, such as reading to them or playing soothing music, can help distract from feelings of restlessness and promote relaxation. Also ensure that their physical comfort needs are met by adjusting their position or providing pain relief as needed.

Congestion: Congestion at end of life may sound like gurgling sounds inside the chest, often referred to as a "death rattle." This sound happens when mucous and saliva accumulate in the person's throat. As a person approaches the end of life, they may become weak or lose consciousness, causing them to lose the ability to clear their throat or swallow. The death rattle sounds like a wet, gurgling, or rattling sound as the person breathes. This sound can resemble gentle bubbling or crackling and may vary in volume, often intensifying as breathing becomes more irregular. These sounds may be loud and can be distressing for others. It is important to note that congestion or the death rattle does not indicate the onset of severe pain. Terminal respiratory secretions are a sign that a person is transitioning to the final stage of the dying process.

Supportive Actions: Gently turn their head to the side to drain secretions. Gently wipe their mouth with a moist cloth and offer lip balm to keep them comfortable and hygienic.

Seeing Visions or Hallucinations Unrelated to Mental Illness or Substance Use: It is not uncommon for people to report that they are seeing people who are already deceased or to describe going to places or seeing things not visible to others. It is a common symptom of the end-of-life process, and may even provide comfort, reassurance, or a sense of connection to the spiritual realm.

Supportive Actions: It is important to approach the person with empathy, openness, and respect. Do not contradict, explain away, or discount this experience. Instead, affirm them and acknowledge the significance of their experience to provide reassurance. Reassure them it is common and natural: "Yes, these things happen."

Consciousness Fades: Before death, the person may become completely unresponsive, as if they are in a coma. When this happens, they cannot be roused, will not open their eyes, and are not able to communicate nor respond to touch.

Supportive Actions: Continue with comfort measures, such as playing their favorite or soothing music, quietly sitting with them, reading from a book they enjoy, singing, etc. Many times, even though the person cannot respond, they can hear and know who is present around them.

Other Possible Changes:

- The person's skin, body fluids, and breath may take on an odor that smells like nail polish remover. This results from changes in their metabolism.
- Open wounds may appear rapidly at the end of life as the skin, like other organs, stops functioning.
- Pain may increase as the disease progresses; chronic conditions, such as arthritis or stiff and inflamed joints, worsen; or pressure injuries to the skin increase.
- A surge of energy, also called "terminal lucidity": In this phenomenon, the person becomes clear-headed in their final days, hours, or minutes. They may seem to have a surge of energy and alertness. How long this surge lasts varies from person to person. Although it is not clear why this happens, it is not a sign that they are getting better.

The Emotional Aspects of End-of-Life Care

End-of-life care brings up complex emotions for both people and those providing care, all of which are normal human responses to the loss of life.

Table 4 lists the commonly experienced emotions by someone receiving or providing end-of-life care. These emotions can be experienced in any order and are repeated throughout the course of care.

TABLE 4 – COMMON EMOTIONAL RESPONSES AT END-OF-LIFE

Emotions	Description
Shock, Disbelief, or Denial	This can show up as numbness, depression, anger, confusion, or loneliness.
Fear	This can be a driving emotion for many of the other emotions listed. Having a trusted person or professional to talk with regarding the concerns that are feeding these fears can help people navigate and connect seemingly disparate emotions. Some examples of fear include: • Worries about where they might die (e.g., the hospital vs. home) • Fear of being alone when they die • Fear they will experience suffering or pain as they die • Fear of not knowing what happens after death • Concern or fear that their life had no purpose or meaning, or that they won't be remembered positively
Anger	This could be connected to other emotions as well. The person may feel they are too young to be dying or that they have "unfinished business" to tend to. This can also show up as frustration, rage, anxiety, or fear. Anger can be rooted in fear.

Regrets and Bargaining	Regret often overlaps with anger, bringing about the question "Why me?" and wondering the reason for what is happening to them. Bargaining can involve various efforts to try to make things different (e.g., "I will promise to do X, if I'm able to live" or "If I could only go back and do X differently, I wouldn't be in this situation."). Bargaining can show up as frustration, sadness, depression, or anger.
Depression	This may look like not getting out of bed, neglecting personal hygiene, retreating from people and activities (different from detachment or withdrawal during active dying), sleeping more (again different from increased sleeping related to active dying), overeating as a form of self-comforting or not eating due to depression (rather than the body shutting down), and self-pity. If someone experienced depression prior to their terminal condition, they are more likely to experience it at the end of life. This is often the longest and most frequent emotional stage of dying.
Loneliness	Loneliness can happen even when you have people around you. The dying process can be isolating, and loneliness happens most often when someone doesn't have people around them whom they feel comfortable talking with about how they feel. Loneliness can also happen when the person stops engaging in social activities that they enjoy.
Acceptance	The emotional stage where a person can engage in conversation on what they would find meaningful and supportive as they move into active dying.

General Supportive Actions

For processing the experience of dying, the best thing that can be done is to provide a safe and supportive space to process the reality of the situation and its inherent complexities. For many of these emotions, attempts to fix, provide advice, or placate often don't work. A staff member or volunteer's job is often to be there as a quiet supporter and companion. For regrets, supportive action can look like helping a person to identify small acts or accomplishments achieved throughout their life. It is ok to think outside the box about what is considered an accomplishment.

Preparing for Spiritual Needs

Having a terminal illness can cause someone to look for meaning in life. Some people find this answer within spirituality. Spirituality can mean different things to different people. People's spiritual needs can vary and change over time. Spirituality is not the same as religion, yet for some people the two may be linked. While spiritual needs may be linked to emotional needs, they are not the same. Emotional needs are connected to people's thoughts and feelings, whereas spiritual needs are often related to a sense of meaning and purpose to their life. Spiritual needs can show up as the need:

- to identify what gives their life meaning purpose and or value
- to feel a sense of belonging, hope, peace, and gratitude

- to share their life story and how they wish to be remembered
- to connect with religious practices and traditions
- to ask for forgiveness and forgiving others
- to answer questions like “Who am I and why am I here?”
- to address spiritual distress or difficulty meeting spiritual needs

Spiritual distress occurs when a person begins to question their beliefs or when they begin to worry that their actions in life conflict with their spiritual beliefs. They may blame God or other spiritual figures for their illness, seek forgiveness for transgressions, or believe that their actions are unforgiveable. Spiritual distress can cause both mental and physical pain.

There are different things that can cause spiritual distress in people with a terminal illness.

- Relationships: loss of family, community, or important people in one’s life; dwelling on past losses; or feeling lonely or experiencing unresolved issues from relationships
- Loss of independence: loss of identity (based in their own competence or caregiving) or worry about not having someone to care for them or being a burden on others
- Fear of dying: worry about the dying process and what happens after death
- Loss of control: over physical and mental health, the future, physical surroundings, and life in general
- Loss of meaning: being unable to find meaning in life or in past experiences

Spiritual Conversation Prompts

The below tool called HOPE, covers some basic topics and can help start the conversation to assess a program participant’s spiritual needs.

H: Hope

- What are your sources of hope, strength, comfort, and peace?

O: Organized religion

- Do you have a religion or faith?
- How important is your religion or faith to you?

P: Personal spirituality and practices

- Do you have personal spiritual beliefs that are separate from organized religion? What are they?
- What aspects of your spirituality or spiritual practices do you find most helpful to you personally?

E: Effects on medical care and end-of-life issues

- Has your illness stopped you from doing things that give your life meaning and purpose?
- Are there any specific practices we should know about when we care for you?

For program participants who are not strongly connected to a spirituality or religion, here are a list of general prompts to assess if they have spiritual needs:

- “What's important to you?”; “What gives you hope?”; and “What was important to you that, because of your illness, you're now unable to do?”
- Try to encourage program participants to talk about how they're feeling.
- Listen for clues that the program participant is struggling with spiritual issues. They might speak about searching for meaning, feelings of isolation, or fear of the unknown.

Chaplains and those in spiritual care roles are trained to assess spiritual distress and can help to identify the program participant’s spiritual needs. Most hospice teams have a chaplain available for support.

Supportive Actions

Spiritual care involves listening to what is important to the program participant. Chaplains, spiritual care coordinators, counselors, psychologists, social workers, and faith leaders are great resources to tap into for addressing spiritual care needs.

Transitioning to Hospice or Inpatient Setting

There may be times when a program participant needs or desires a higher level of care than a medical respite program is able to provide. It can sometimes be difficult to find an inpatient or skilled facility bed for a participant. And while these settings may provide comfort and reassurance in some ways, they are not always able to adjust their operations to accommodate the needs of our program participants, such as flexible visiting hours, presence of pets, or substance use. It is beneficial to weigh the pros and cons of transitioning a program participant to a formal inpatient hospice or skilled nursing facility setting on a case-by-case basis, balancing participant need with medical respite capacity.

You can refer to the sections on *Admissions and Assessments* and *Partnering with a Hospice Provider* for more information on making decisions about transfers outside of the medical respite setting.

Delayed Transfer Plan

Transfer to a skilled nursing facility or inpatient nursing home can be delayed for a variety of reasons, including lack of bed availability or trouble getting a location to accept. It is wise to have a backup plan in place for when situations like this arise.

Practical Aspects of Responding to Death

After a program participant has died, both the medical respite management team and the hospice team need to be notified, provided the participant was enrolled in hospice. If the program participant was not officially enrolled in hospice, the medical respite team would need to call 911. The paramedics will show up to pronounce the program participant as dead and the police will be called to initiate the coroner pick-up process.

The next step would be to call the funeral home and any family or contacts identified by the program participant who died. Who makes those calls will depend on the agreement between the medical respite and hospice.

After Death and Before the Funeral Home or Coroner Arrives

Make other staff and program participants aware that the participant has died and that their body is still in the building. Consider closing the door of their room, if private, or covering their body with a sheet.

Preparing Body for Pickup: This can look different based on your medical respite program and if the program participant was officially enrolled in hospice. For some, bathing the body after death as a way of saying a final goodbye is a grief ritual they find beneficial. This might also look like wiping the person's face and putting them in a comfortable or resting position. If the patient was not enrolled in hospice, these are not options due to the coroner needing to assess the situation. Instead, staff could follow the body out to the coroner van with a lit candle (real or battery-operated) and keep it in a safe communal area for seven days.

Building a Local Continuum of Care and Quality Improvement

Building a Continuum of Care

Medical respite programs have multiple partnerships, both within the healthcare and housing continuum. Developing partnerships is not new to program operations (such as relationships with health centers or home health care), and the process that is used for those partnerships can be followed to expand end-of-life care services. Medical respite programs will need to establish new and different partnerships to become part of a community's continuum of end-of-life care and to ensure safe and quality services. The next sections suggest various partnerships that can provide support for those needing hospice and end-of-life care based on the medical respite process.

Appendix B provides a tool to identify and organize potential partnerships for providing end-of-life care or to identify partnerships that are needed.

Referrals and Admissions

Partnerships for referrals and admissions include entities that would refer a person to the medical respite program for end of life or to receive hospice care; they could provide the necessary information for the program to make an admissions decision. These partners may also identify a hospice provider for the person, initiate the hospice care process to prepare the person for entering the program, or perform a case review prior to admission to ensure appropriateness for the program. Partnerships that support the referral and admissions process to those people needing end-of-life care in medical respite programs may include:

- Hospitals
- Specialty care providers (e.g., cancer specialists, dialysis providers)
- Hospice providers
- Street medicine and street palliative care providers
- Health centers
- Shelters

Medical respite programs will need to communicate their referral criteria to each partner and ensure the admissions process (described in the section *Admissions and Assessment*) is completed with each partner.

Providing End-of-Life Care

Previous sections of this guide have identified several resources and the staff needed to be able to provide end-of-life care within the medical respite setting. Listed here are potential partners unique to providing end-of-life care or supporting people at end of life, ranging from those providing medical care to social and spiritual supports:

- Hospice providers
- Home health care agencies (as indicated)
- Caregiver supports (if not provided by hospice agency)
- Death doulas and peer supports
- Spiritual supports, including those who provide support specifically at end of life
- Behavioral health services, especially those who are equipped or trained for individuals approaching end of life and grief support
- Providers who are knowledgeable and can support the advanced directive process
- Attorneys who are able to manage wills, family reconnection, and end-of-life legal issues
- No One Dies Alone
- Volunteer programs for activities and recreation
- Last Wishes programs and organizations

Higher Levels of Care

In the case that a person may require more care than can be provided in the medical respite program through supportive partnerships, the program should have pathways and partnerships with entities that the person can transition to if and when this care is needed. These include:

- Community-based hospice facilities or homes
- Inpatient hospice units (at hospitals or skilled nursing facilities)

Posthumous Resources and Services

Medical respite programs will need to have a process for managing the program participant's body and wishes for after their death. Additionally, partnerships should be made so that staff and program participants have adequate support for grieving and responding to the death of a participant in the program. Partnerships to address these needs include:

- Funeral home and cremation services
- Local coroner offices
- Spiritual supports for program participants and staff

Appendix B provides a tool to identify and organize potential partnerships for providing end-of-life care.

Working Collaboratively with All Partners

Collaborative care is a Guiding Principle for providing medical respite care. Collaborative care in medical respite programs identifies the importance of communication, both within the program among the staff as well as with community partners and outside agencies, to ensure "the priorities and needs of the client can be addressed holistically, ensuring communication and support throughout the medical respite stay."[17]

Effective collaborative partnerships are especially critical in end-of-life care to prevent unneeded discomfort or suffering of the program participants, ensuring that the program and staff are effectively supported and that services remain participant-centered throughout the process.

The Homeless Palliative Care Toolkit has a section focused on collaborating and working with multiple agencies to effectively provide end-of-life care; it should be reviewed as partnerships are established and maintained.

Quality Improvement

Quality Improvement (QI) related to hospice and end-of-life care can be more challenging in the medical respite setting. Many of the satisfaction scales that exist for end-of-life and hospice care rely on families and caregivers to complete assessments about the agency's ability to provide adequate support at end of life; this perspective may not be available to be captured for those in medical respite programs. Additionally, programs may be hesitant to implement surveys and measures with those program participants in hospice and close to end of life.

Evaluation and quality improvement are part of the Standards for Medical Respite Care Programs under Standard 8. Evaluating end-of-life care should be part of the routine data collection and QI process for programs; however, specific metrics and outcomes may be slightly different.

In the medical respite care setting, programs may assess their ability to provide hospice care through evaluating outcomes of the program participants who receive hospice or end-of-life care, staff experiences, and partnerships that provide care.

Evaluating Outcomes of Program Participants Served

Programs can use recommended outcomes for medical respite care programs to evaluate the program's data around serving program participants at end of life, including:

- Demographics of program participants receiving hospice care
- Diagnoses and reason for referral (e.g., how many program participants may have transitioned into hospice care while at medical respite vs. those who were referred primarily for hospice)
- Referral source data
    - Palliative Performance Scale scores of those admitted to the program, along with social determinants of health or support needs
    - All individuals who are referred for end-of-life care at the program, including those who are not admitted and reason(s) that referrals were declined
    - Measures of time to first Hospice or Palliative Care Assessment to determine how long it takes for services to come see participants of the program
- Discharge, transition, and end-of-life data

  - How many participants transitioned to higher levels of care
  - How many participants transitioned to inpatient hospice programs
  - How many participants were able to die and complete end-of-life care within the medical respite program
  - How many program participants improved and were able to transition from hospice care (or return to the community)
- Goals identified as part of the care plan and achievement of these goals
  - Completing advanced directives
  - Identifying end-of-life wishes
  - Reconnection with family and support systems
  - Connection with end-of-life supports (e.g., chaplains, death doulas)
- Clinical outcomes
  - Pain management
  - Secondary condition management (e.g., delirium, infection)
  - Use of behavioral health services
  - Number of hospice program visits
- Participant and caregiver experience surveys
  - Although not always appropriate to administer, there may be program participants who are interested and able to complete surveys regarding their experience.
  - In the cases where family and support systems are involved in the program participant's end-of-life care, surveys may also be administered regarding their experiences of how the program provided support and care.
  - The Consumer Assessment of Healthcare Providers and Systems Hospice Survey is available from the Centers for Medicare and Medicaid Services (CMS).

Programs can use data regarding program participants served and the outcomes of care to identify the overall impact of the program, identify gaps in care, and identify areas for improvement. Demographic data and information collected on referrals to the program (including both individuals who were and were not admitted) can be reviewed to ensure that there is equal access to hospice and end-of-life care across populations.

Data that points to issues in access can promote quality improvement of programs by prompting outreach to referral sources to increase referrals of underrepresented groups and establish new referral partnerships, or to explore other barriers to care.

Further, programs may opt to partner with their hospice provider(s) to participate in their quality metrics and improvements and compare the data of those served within medical respite programs vs. the general population to ensure that care and outcomes are the same across populations.

Care plans and clinical outcomes can identify additional areas of improvement or indicate a need for additional staffing (e.g., dedicated case manager for hospice patients due to the complexity and timeliness of case management needs) or a need for advocacy with partnering medical and hospice providers (e.g., more pain management avenues).

Staff Measures

When programs provide end-of-life care, they should also consider the impact on and outcomes for staff. Programs should explore questions such as:

- Do staff feel equipped and supported to provide end-of-life care?
- Do staff feel like they have adequate training to support program participants at end of life?
- Do staff feel like they have adequate support for their grief and processing the death of program participants?
- Do staff feel like the program partnerships are effective and supportive of their work?

Any surveys administered to staff should be anonymous and may need to be implemented by a third party to ensure staff feel comfortable sharing their experiences. Gaps identified should be used to inform QI planning in addition to the program participant outcomes.

Quality of Partnerships

Because providing end-of-life care in medical respite relies heavily on effective partnerships, QI efforts can also focus on evaluating existing partnerships.

On a small scale, programs can evaluate partnerships by:

- Surveying staff on perceived effectiveness or barriers in partnerships and how these impact program participants' care.
- Reviewing specific program participant cases or care plans to see how the effectiveness of partnerships affected care.
    - For example, a medical respite program that finds that pain is not effectively addressed or well-managed among its participants may examine their partnership with the hospice program and its prescribing providers. This investigation may find that providers are not responsive to calls from program staff because they are not family or caregivers; are reluctant to adequately prescribe pain medications for people with substance use histories; or are overworked due to understaffing at the hospice program, resulting in overall reduced care. This may result in the program exploring additional partnerships or working with the hospice agency leadership by sharing data and outcomes to address the issues identified.

More in-depth guides to analyzing partnerships can be found here:

- Partnership Impact Evaluation Guide
- Indicators That Measure Organizational Partnerships

The following resources and references would be helpful to review as part of QI planning:

- CAHPS Hospice Survey Fact Sheet
- About the CAHPS Hospice Survey
- Armstrong, B., Jenigiri, B., Hutson, S. P., Wachs, P. M., & Lambe, C. E. (2013). The impact of a palliative care program in a rural Appalachian community hospital: A quality improvement process. *The American Journal of Hospice and Palliative Medicine*, *30*(4), 380–387. https://doi.org/10.1177/1049909112458720
- Quigley, D. D., & McCleskey, S. G. (2021). Improving care experiences for patients and caregivers at end of life: A systematic review. *The American Journal of Hospice and Palliative Medicine*, *38*(1), 84–93. https://doi.org/10.1177/1049909120931468
- Rajaram, A., Morey, T., Shah, S., Dosani, N., & Mamdani, M. (2020). Providing data-driven equitable palliative and end-of-life care for structurally vulnerable populations: A pilot survey of information management strategies. *The American Journal of Hospice and Palliative Medicine*, *37*(4), 244–249. https://doi.org/10.1177/1049909119872756
- Robinson, L., Trevors Babici, L., Tedesco, A., Spaner, D., Morey, T., & Dosani, N. (2023). Assessing the impact of a health navigator on improving access to care and addressing the social needs of palliative care patients experiencing homelessness: A service evaluation. *Palliative Medicine*, *37*(4), 646–651. https://doi.org/10.1177/02692163221146812
- Schneider, E., & Dosani, N. (2021). Retrospective study of a Toronto-based palliative care program for individuals experiencing homelessness. *Journal of Palliative Medicine*, *24*(8), 1232–1235. https://doi.org/10.1089/jpm.2020.0772

Program Example: Welcome Home

Welcome Home, founded in 2015, serves as a medical respite and end-of-life care facility for people experiencing homelessness in Chattanooga, Tennessee. They currently operate one 4-bedroom hospice home and two 3-bedroom homes for cancer respite. In 2024, Welcome Home served 31 individuals and provided continued case management through their Graduate Program, where they are currently serving 12 graduates whose health stabilized and were then transitioned into permanent housing. Celebrating their 10th anniversary, they have served over 130 people and have had over 500 volunteers, students, and visitors. Welcome Home operates within the structure of care in which a person enters the program, end-of-life care is provided onsite by a hospice partner, and they remain at Welcome Home through the entire end-of-life process.

Referrals to Welcome Home can come from various sources including hospitals, medical clinics, police departments, churches, or other homeless service agencies. The program also recently began accepting self-referrals. Funded through a mix of private donations, faith communities, local business foundations, and grants, staff emphasize the importance of building relationships in the community and promoting the work that they do. The success of these relationships reaches beyond financial contributions, as a robust network of volunteers supports program operations every day.

What began as a traditional hospice facility for people experiencing homelessness changed in 2021 when the program realized they were caring for individuals who were dying prematurely from cancer. Unstable living circumstances were preventing numerous people from accessing cancer treatment, a need that Welcome Home wanted to meet. A partnership with the Chattanooga Tumor Clinic led to the creation of the Cancer Respite Program. Now, in addition to the 4-bedroom hospice home, two homes, containing six beds, sit next door to the main facility and are dedicated to individuals who need shelter during cancer treatment. Residents can stay for end-of-life care as long as they are eligible for hospice care, which is determined by having a prognosis of six months or less. If a resident’s health improves, their case management goal shifts to securing housing placement, and they can move into the Graduate Program. The care team reviews the client's progress over 90 days to determine if an alternative placement should be secured.

Clinical care for clients in the hospice home is provided by the residents’ hospice team. Residents of the cancer respite homes receive care through a combination of an oncology team, the Chattanooga Cancer Center, and/or a hospice team when indicated. The program employs a social worker and caregivers to provide 24-hour support to residents. An extensive network of volunteers includes the “Go-Go Club,” a group of approved volunteers that assist with transportation to doctor and treatment appointments, Dinner Club for meal services, chaplains, and Companions. Companion training is intensive training similar to what staff receive, requires 2-4 hours of volunteering a week, and a minimum 6-month commitment. Welcome Home also hosts volunteer groups from the community for social and recreational events, including Garden Club, Fundraising, and Office Support group.

Medication is managed by the hospice partner and/or the oncology team. The program can support the clients with filling pill boxes, but they must log medications and follow orders from the partner providers.

Clients work with case managers who help them apply for benefits, reconnect with family, complete an advanced directive (e.g., Five Wishes), and engage in various other supportive services. A celebration of life is held for clients who pass away, and their name is added to the Memory Tree mural in their main building. These celebrations can be planned by the client in advance and often include music, candles, sharing of memories, etc. All staff, residents, and volunteers are able to attend. An on-call counselor is also accessible, and staff are eligible for and encouraged to use compassion fatigue relief, a paid relief opportunity for grieving and self-care. Welcome Home has partnered with a local funeral home and sets aside funds yearly to assist with cremations. Some individuals choose to donate their bodies to science, while others request that their remains be returned to Welcome Home.

Welcome Home offers a 6-week course called *Demystifying Death* in which participants can learn how to come to terms with death and how they can help others in that journey. The course details the basics of death and dying with the goal of becoming more informed and comfortable with end-of-life care. Learners complete an “end-of-life packet” and learn about the Five Wishes, The Dying Person’s Bill of Rights, and other concerns related to death. Two cohorts are held each year (one in the fall and one in the spring), and applications are open to members of the public.

Learn more about Welcome Home:

October 2022 WTCI PBS Greater Chattanooga, “The Walk Home”

Blue Cross Blue Shield, "Welcome Home of Chattanooga"

Better Tennessee, "Will Anybody Find Me"

Chattanooga Times Free Press, "The Comfort of Home at The End of Life"

US News: **Chattanooga Homeless Hospice Center Opens Cancer Home**

Resources from Welcome Home

Welcome Home Newsletters

Welcome Home 2023 Annual Report

https://www.welcomehomeofchattanooga.org/

Demystifying Death Course

Program Example: The INN Between

The INN Between, founded in 2015, is a medical respite and end-of-life care facility for people experiencing homelessness in Salt Lake City, Utah. The program started as a pilot project, but the program's purchase of a former skilled nursing facility in 2017 led to an expanded 50-bed facility. As of August 2024, The INN Between has provided a housing and caregiving solution to help 140 individuals in their community die with dignity. The INN Between operates within the fourth structure identified in this guide: where a person enters the program, end-of-life care is provided in the medical respite via a hospice partnership, and the participant remains for the duration of their life.

Referrals to the program can come from various sources including hospitals, medical clinics, police departments, churches, or other homeless service agencies. Funded through a mix of private donations and foundations, the organization does not turn away people who are unable to pay. Additionally, pets are accepted into the program. Through partnership with local animal welfare agencies, permanent placement is found for the animals once residents are unable to care for them. The INN Between also holds firm in its philosophy to "wipe the slate clean" and allows everyone an opportunity to die safely housed with access to hospice care, including those with criminal backgrounds.

If an individual has a hospice designation, the hospice agency and The INN Between staff meet with them upon admission to discuss care plans and supportive services. Once admitted, the program participants receive all basic needs (food, shelter, clothing, etc.), transportation to all medical appointments, intensive case management, and substance use recovery support, including daily transportation to methadone clinics if needed. Program participants also have access to activities that promote wellness, facilitate positive interaction with others and the community, and encourage self-sufficiency.

Clinical care is provided to program participants on-site through partnerships with local hospice agencies. The program does employ RNs and 24/7 CNAs who can help with medications and vital checks, but all medications are prescribed and pre-packed by hospice providers. Pain management is overseen by hospice providers, but respite care staff monitor for changes in condition and advocate as needed. Other non-clinical staff offer wellness checks at least once a day, and they are trained in basic medical care and person-centered approaches. Program participants also work with case managers who help them apply for benefits, reconnect with family, complete an advanced directive, and engage in a variety of other supportive services.

Once participants agree to come to The INN Between, they are then called residents, and the staff act as family members to facilitate an inclusive, supportive environment. The INN Between relies heavily on volunteers from local organizations and holds training to incorporate community members into program operations. They also utilize the No One Dies Alone volunteer program, ensuring that residents have someone to sit beside them and support them until the end. Volunteers host jewelry-making classes, prepare meals, provide haircuts, and facilitate recreational activities for residents to enjoy. Spiritual volunteers offer multi-denominational religious and non-religious emotional support if residents are interested. In the most recent fiscal year report, more than 3,053 volunteer hours were logged, with a reported savings of $88,500 to the organization.[18]

The INN Between serves both individuals in need of hospice care and provides general medical respite care. The building is designated into two domains, and residents receiving hospice care are offered single rooms for privacy. Sometimes, upon arrival in the program, residents experience difficulty coming to terms with a life-limiting diagnosis. Additionally, some may arrive at medical respite with a palliative or general medical need and then experience a decline in condition. In these instances, residents can stay on the "medical respite side" and then transition to the "hospice side" once they are comfortable or require a higher level of care. In some cases, residents improve after entering hospice care, and their health concerns are addressed in a stable environment. For example, a former resident recovered from illness and became trained as a death doula. She now lives on-site and continues supporting peers through their health journeys.

The INN Between is licensed as a Level II assisted living facility, allowing staff to assist with ADLs. If an individual cannot be supported by the hospice partnership and The INN Between, they can be transferred to an inpatient hospice facility or hospital, though this rarely happens. Residents are educated upon their arrival on what to expect and can engage in planning how they would like to spend their remaining time. The program offers a last meal and other special activities focused on resident choice. Creating a warm and home-like environment also includes offering recreation and activities so that residents know they are part of a loving community.

Once hospice residents begin experiencing a decline in health, a butterfly is placed outside of their room to let others know their status and how to approach them. After a resident passes, the hospice provider is notified and assists with the next steps. The county can assist with cremation services as needed, and a donation fund exists to contribute to those expenses. A candle lighting and celebration of life is held by the program, and the butterfly from the door is moved to a numeric mural of butterflies that identifies how many people have passed with dignity in the facility. The INN Between posts resident obituaries online and has an outdoor Memorial Garden where all names of individuals are etched into stone. A community memorial service is held at the wishes of the residents or their families.

Staff training and memorial services have evolved as the need changes. Grief support is offered to staff and residents, and the program relies on feedback to adapt its processes. As death is often a difficult circumstance to navigate, it is vital to provide balanced training regarding the logistical considerations for staff, along with the behavioral and emotional needs of everyone affected. Although this is challenging work, The INN Between prides itself on its success in providing its residents with a safe and supportive community in which they can spend their remaining days comfortably, knowing they are loved.

Recommended Resources Featuring The INN Between

- 2023, *DeseretNews* featured The INN Between in a multipage story with award-winning photo journalism entitled "The place where no one dies alone."
- 2023, VRT Belgium created a 25-minute documentary about The INN Between.
- 2022, the *Los Angeles Times* featured The INN Between on its front page
- 2018, Utah Housing Matters, ***Agency of the Year Award***

- 2017, KUED Channel 7 created Homeless at the End, a one-hour documentary about The INN Between and the realities of facing death on the streets.

Resources from the INN Between

- The INN Between's 2023/2024 Annual Report
- Jensen, F. B., & Thorpe, D. (2024). Social model hospice: Providing hospice and palliative care for a homeless population in Salt Lake City, Utah. *Journal of Hospice & Palliative Nursing*, *26*(2), 91-97. https://tibhospice.org/stories/social-model-hospice-article-published

Program Example: San Francisco Department of Public Health Medical Respite Program

The San Francisco Health Network Medical Respite Program was established in the early 2000s. Inpatient teams at San Francisco General Hospital witnessed the cycle of hospitalized patients getting discharged to shelters or the street without support to manage follow-up needs, only to return to the ER to be admitted, medically stabilized, and discharged back to the same environment again without support or resources in place. In an effort to disrupt this cycle, the San Francisco Department of Public Health opened a 12-bed medical respite program embedded within one of the city's homeless shelters, establishing the first medical respite program to be publicly funded by a public health department. In March 2007, the program moved into a stand-alone facility and increased its capacity to 45 beds. The program expanded again in 2018 to 75 beds. The program's 75 beds are dorm style with 4 male congregate dorms and 7 female semi congregate rooms, with 2-4 residents each.

Clients can be referred to the program in one of two ways: either from the acute care setting after a hospitalization or from the community via the Shelter Health Program if they are having challenges managing their medical needs in the shelter environment and could benefit from medical respite support.

The San Francisco Medical Respite program is a collaboration between the San Francisco Department of Public Health and Community Forward, a local community-based organization. The Department of Public Health provides clinical services such as primary care, nursing, social work, and case management, and Community Forward provides the sheltering, transportation, and hospitality services. While the medical respite program started over 18 years ago, with symptom management and linkage to external palliative care services were part of the general care offered as needed, onsite hospice services weren't officially added until 2021. In 2021, the medical respite program established a partnership with Hospice by the Bay, a local home-based palliative care and hospice agency. This partnership allowed the program to expand its capacity to provide a continuum of care from palliative care services up to end-of-life transitions.

Advance directives, hospice enrollment, and end-of-life planning conversations are handled by the providers on the clinical team, either an NP, PA, or MD. Providers then refer and connect participants to either the palliative care or hospice team at Hospice by the Bay, depending on the clinical situation and personal health goals.

Symptom management medications are prescribed by the Hospice by the Bay palliative care or hospice team prescribing provider. These teams are well-versed in providing pain medication management for people with a history of substance use. Symptom management medications are delivered in pre-packaged medisets for the medical respite nurse to distribute daily to enrolled medical respite patients, who then self-administer their medications. If new or uncontrolled symptoms develop after hours when there is no onsite medical respite nursing staff, onsite medical respite workers, or on-call clinical staff, assist the individual in connecting with the Hospice by the Bay palliative care or hospice team for support. The Hospice by the Bay team determines if they can deliver extra medications or if the client should be directed to the hospital.

The goal of this collaboration is to allow individuals to remain in the community as long as possible if that is their goal. Individuals are able to participate in the medical respite community while being enrolled in hospice for as long as they are able to meet the program's functional requirements, including getting in and out of bed independently, toileting independently, self-administering medications, and being able to participate in community dining. Given the congregate community and the program's staffing model, the San Francisco Medical Respite program is not able to support individuals as they reach the end of life. When someone is no longer appropriate for the medical respite setting, the Hospice by the Bay team arranges for the individual to be transferred to a hospice facility or the hospital, if more appropriate. The partnering hospice agency prioritizes placement into one of its small home-style settings over hospital-based hospice whenever possible.

Appendix A

Timeline for End-of-Life Changes

Every end-of-life journey is unique to the person experiencing it. The timeline below is to simply provide a general understanding of the common points in the journey.

One to Three Months Before Death

- Decreased desire for food
- Increased desire for sleep
- Withdrawal from people and the environment
- Talking less

One to Two Weeks Before Death

- Even more sleep
- Confusion
- Restlessness
- Vision-like experiences
- Change in temperature, respiration, heart rate, and blood pressure
- Congestion
- Little to no eating and decreased drinking
- Fewer and smaller bowel movements, less urine production

Days or Hours Before Death

- Surge of energy also called “terminal lucidity”
- Decreased blood pressure
- Glassy, teary eyes
- Half-opened eyes
- Irregular breathing
- Increased restlessness
- Cold, purple, and blotchy feet and hands
- Weak pulse
- Decreased urine output
- Unconsciousness

Minutes Before Death

- Gasping breathing or no perceptible breathing
- No awakening

Additional Considerations

- Dying may take hours or days. No one can predict the time of death, even if the person is exhibiting typical end-of-life signs and symptoms.
- The best way to be with the dying is to follow their lead. If they feel like talking, great. If they are sleepy, bring something to read. Just sitting and being present in the room with them is very reassuring.
- It can be very healing for the dying person to know that their life mattered and they will be remembered.

Community Resources and Partnerships to Support End of Life Care

Type of Program	Description of Services	Local Agency that Provides this Service	Local Agency that Provides this Service	Local Agency that Provides this Service
Palliative Care Providers	Providers who are able to provide palliative care by focusing on improving quality of life for people with serious illness and their care partners. This includes managing a person's symptoms and coordinating care effectively. Palliative care providers may be located within hospital systems, outpatient palliative care clinics, and street medicine teams. You can identify local palliative care providers here: https://www.nhpco.org/find-a-care-provider/	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Hospice Care Providers	Providers who are able to implement hospice or end-of-life care. These providers focus on the care, comfort, and quality of life for a person who is approaching end of life. A person may be referred to hospice care by their specialty or primary care provider.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:

Community Resources and Partnerships to Support End of Life Care

Type of Program	Description of Services	Local Agency that Provides this Service	Local Agency that Provides this Service	Local Agency that Provides this Service
Hospice Facilities	This may be a standalone facility that provides hospice care 24/7 to residents of the program. These facilities may also be embedded within nursing homes or skilled nursing facilities. In some cases, the person may also complete hospice care in a specialized hospital setting.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Caregiver Agencies	May also be called a "home care agency" where staff go to a person's home (or medical respite program) to provide non-medical or medical assistance with activities such as activities of daily living. In some cases, caregiver agencies can also provider companionship.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Behavioral Health Providers, especially with resources related to processing end of life	Providers who address mental health, resilience, and wellbeing; the treatment of mental and substance use disorders; and the support of those who experience and/or are in recovery from these conditions (SAMHSA, 2014). The use of the term "behavioral health" encompasses both mental health and substance use.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:

Community Resources and Partnerships to Support End of Life Care

Type of Program	Description of Services	Local Agency that Provides this Service	Local Agency that Provides this Service	Local Agency that Provides this Service
Spiritual or Religious Support	People or entities that provide spiritual, guidance, counseling, and/or worship services allowing people to practice their faith and access support related to religious beliefs. Programs should identify a range of providers/resources in their community as well as potential virtual resources.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Providers or Consultants for Completing Advanced Directives	This may be provided by the hospice care agency, but may also include legal advocates or the person's primary care provider. More resources on advanced directives can be found here: [National Institute on Aging Advanced Care Planning Conversation Guide]()	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Last Wishes programs	Programs that focus on meeting a person's "last wishes" before end of life. These activities can include meals, trips or community outings, or other activities identified by the client.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:

Community Resources and Partnerships to Support End of Life Care

Type of Program	Description of Services	Local Agency that Provides this Service	Local Agency that Provides this Service	Local Agency that Provides this Service
No One Dies Alone or other Hospice Volunteer Programs	Organizations or volunteers that focus on providing companionship during end of life, and to provide an additional (or possibly) the primary support system. To learn about No One Dies Alone organization and find related resources here: https://nosdaf.com/about/	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Death/ End of Life Doula	An end of life doula provides companionship, comfort, and guidance to those planning for death, diagnosed with a terminal illness, or facing imminent death. Learn more about end-of-life doulas, receive training, or find a doula here: https://inelda.org/about-doulas/what-is-a-doula/	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Funeral Home/ County Cremations	A funeral home provides burial and cremation services. Programs will want to identify homes that are able to provide low cost or pro bono services for their clients. County cremation services will provide cremation to deceased individuals based on specific eligibility requirements, often those unable to afford a private funeral.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:

Community Resources and Partnerships to Support End of Life Care

Type of Program	Description of Services	Local Agency that Provides this Service	Local Agency that Provides this Service	Local Agency that Provides this Service
Attorneys (focused on wills and family reconnection)	Attorneys, including those that will take pro bono cases, who can provide additional support to address remaining legal issues at end of life, including writing and executing wills. Local Legal Aid agencies may be able to provide support or referrals.	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:
Other Resources		Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:	Name: Contact Information: Referral Criteria:

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