exploring your end of life options

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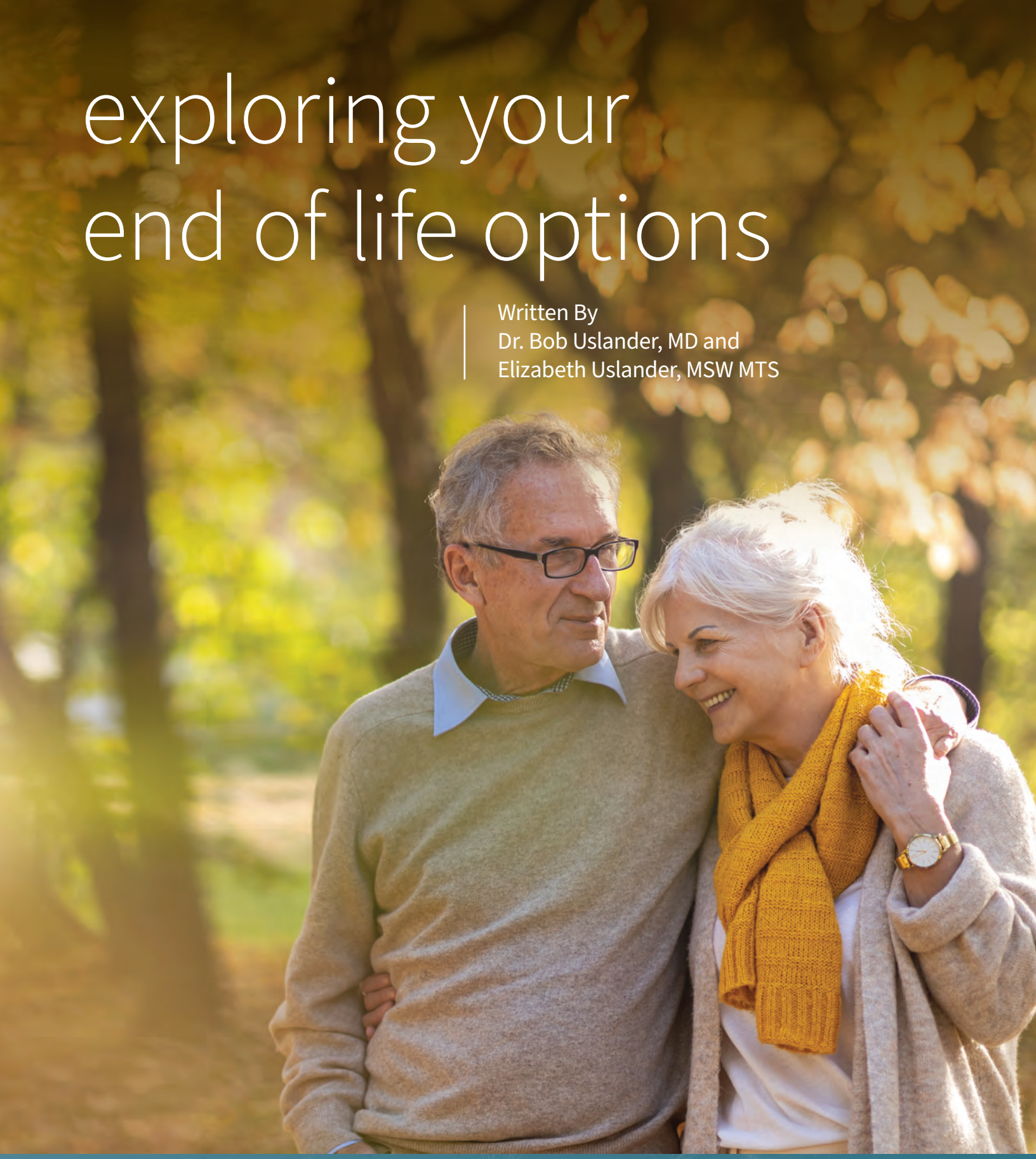

A practical and compassionate guide to help you make the most informed decisions regarding the journey ahead.

EMPOWERED ENDINGS

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1 introduction to end of life options

Many people believe they don't have a choice about how they navigate the end of their life. That's not true, and we are committed to helping people understand this critically important fact.

Most people are disempowered and uninformed about their End of Life experience, and get carried along by a healthcare system that is focused on prolonging life at all costs. Yet there are a number of paths that one could take at the End of Life to ensure that the experience is dignified and gentle instead of undignified and traumatic.

Not only are there options, but there are also healthcare professionals (though unfortunately far too few) who are willing and able to explore the options with you and your loved ones prior to, and during, the last phases of your journey.

At Empowered Endings, we believe everyone should understand their End of Life options. That knowledge can allow each individual to make empowered personal decisions about their final days, weeks, or months of life.

This ebook shares the details on these options, though it's just a beginning. If you have any questions, or are looking for support or guidance, you can always learn more and connect with us through our website at **EmpoweredEndings.com**, or call us at **858-925-7554**.

2 end of life consideration

When considering how to approach the End of Life, one of the first steps is to make some decisions about the quality of life that would be acceptable to you:

- What types of treatments would you agree to?
- What types of treatments are you absolutely not willing to do?
- What activities do you need to be able to do in order to feel that life is worth living?
- What limitations are you willing, or not willing, to accept?
- How much pain are you willing to tolerate?
- What types of living arrangements are you willing to consider?

For example, would you feel you have an acceptable quality of life if you were unable to stand or walk? What if you were on a ventilator or required a feeding tube? What if you were required to live in a nursing home for weeks or months (or years?)

Every person will have a different threshold for what constitutes an acceptable quality of life. One patient we cared for was willing to tolerate a lot of limitations as long as he could watch football and eat ice cream! It's vitally important to consider and discuss these variables and ensure that your wishes are clear to those supporting and caring for you.

It's also crucial to address these issues with your loved ones early in the course of an illness or even before being diagnosed with a serious illness. If it ever comes to pass that you can't speak for yourself, you want to be sure that the people making decisions on your behalf are aware of, and willing to carry out, your wishes. They need to know because it may become the responsibility of your HealthCare Agent (HCA) or Durable Power of Attorney (DPOA) to make important decisions on your behalf. These are the trusted people who you officially assign to make medical decisions for you if a severe illness or injury makes it impossible for you to decide and/or communicate for yourself.

Every person will have a different threshold for what constitutes an acceptable quality of life.

If you haven't explored with your Health Care Agent what you want, and even more importantly what you don't want, it is much more likely that you will be subjected to treatments and circumstances that you wouldn't have chosen for yourself. It's also more likely that your loved ones will find themselves "in crisis" at some point, which can result in a lifetime of guilt and regret.

Health Care Agents commonly feel uncomfortable declining treatments that haven't been previously discussed. The potential conflict extends to the family as a whole, especially when family members disagree about what care should or shouldn't be provided. It may feel uncomfortable at first, but you can protect yourself and your loved ones by initiating conversations that explore your wishes and needs, then documenting them clearly.

Some people don't have a person in their life that they feel would be able to assume this role effectively. Fortunately, there are people who do this for a living—some fiduciaries and attorneys are willing to serve in this capacity. It may be worth exploring professionals in your area who can take on this critical role. Feel free to contact us at Empowered Endings at any time to learn more about this critical issue.

You should have certain documents prepared in case you're unable to communicate when decisions need to be made. The most important of these is the Advance Health Care Directive (AHCD), which describes your End of Life wishes and names your Health Care Agent. Another is the POLST/DNR, which stands for Physician Orders for Life-Sustaining Treatment/Do Not Resuscitate. These forms identify whether you would want CPR and other life sustaining treatments or not.

Another important consideration is where you would wish to live during your End of Life journey. There are many options, each with their pros and cons, which we will discuss in a later chapter.

Whatever path one chooses, being at home with proper support is almost always the best option if feasible. Some of the End of Life options we'll discuss may be difficult or impossible to choose when living in a location other than a private home. Hospitals, nursing homes, assisted living facilities, and residential care facilities (RCFEs) have rules and regulations that may prevent people from following paths like Medical Aid in Dying (MAiD) or Voluntarily Stopping Eating and Drinking (VSED). For this reason, maintaining discretion as one is exploring their options is always recommended.

3 end of life options

1. Do Everything (aka Full Steam Ahead)

"Do Everything" is the default mode in the modern U.S. healthcare system. The "Do Everything" option means following the advice of medical providers without question, accepting any and all treatments and procedures offered or recommended in hopes of staying alive no matter what.

There are certainly times when aggressive and even heroic treatment is warranted and appropriate. However, the "Do Everything" approach at some point can result in panic, anguish, becoming overwhelmed, and far too often, a difficult death.

The "Do Everything" option frequently results in deaths in Emergency Rooms and Intensive Care Units. It can lead to panicked and stressful transitions to hospice care in the final hours or days of life. It can even result in a lifetime of guilt and regret for loved ones who wish they'd done things differently, but can't. Sadly, there are no do-overs with death.

Regardless, some people are willing to fight for every second of life, whatever the consequences. For those, the Do Everything approach makes perfect sense, because it is aligned with their values and provides meaning to their life.

There are other avenues than "Do Everything." It requires careful consideration and advance planning to break away from this mode if it does not feel right for you. If you and your loved ones feel that you're being pushed along the medical "conveyor belt" and are wondering if there is another more peaceful and appropriate way, you can always reach out to us for a complimentary consultation so we can help you explore the options.

2. Allow nature to take its course by stopping aggressive treatment

For those with a terminal illness, there comes a time when harm from medical treatment can outweigh the potential benefits. It can be difficult for patients, their loved ones, and even their physicians to accept that those treatments are no longer viable or effective.

Sadly, a number of curative and palliative treatments can actually increase the likelihood of hospitalization, negatively impact the quality of life, and even shorten one's life. Yet there's a tendency to pursue new treatments in spite of the complications and struggles they can bring. Many doctors are so intently focused on extending life that they fail to address the reality that the limited time gained may be marred by undue pain and suffering.

Patients and loved ones should fully understand the most likely outcomes of their potential treatments, and the impact it may have on their quality of life. You—the patient—should always be at the center. You always have the right to refuse or stop treatment, decline medical intervention, or refuse to go to the hospital. This is your right, even if this decision might lead to a quicker death. This truth applies even if you are not terminally ill.

Doctors, especially oncologists, can find it hard to admit that they have nothing more to offer when patients are deteriorating and dying. Often, they offer a "Hail Mary" in the hopes that you will be one of the lucky few who respond positively to a treatment. What they sometimes fail to inform patients and loved ones is the very likely possibility that the treatment not only won't help, but will make things worse—possibly even hastening death. We've seen this pattern occur more times than we care to remember.

Sometimes when patients decide to discontinue aggressive treatment the doctors that have been their lifelines wash their hands of them. Suddenly, patients and families find themselves without adequate support. This is why people often end up on hospice care inappropriately—we'll discuss that more later. For these reasons, it's critical to ensure that a support system remains in place to receive appropriate management of symptoms that cause discomfort or distress when stopping aggressive treatments.

3. VSED - Voluntarily Stopping Eating and Drinking

Though it might sound extreme to some, stopping eating and drinking is a normal part of the dying process and is typically painless and peaceful. As death approaches, people often lose their appetite and/or become too weak to eat or drink.

For people who wish to hasten their End of Life transition due to prolonged suffering or advanced age, VSED is a legal and reasonable option. Because it is poorly understood, even among healthcare professionals, it is significantly underutilized as a pathway to a dignified and empowered End of Life experience.

VSED is a natural process, and often gives the person a sense of empowerment and control as they prepare to let go of life.

The VSED process involves ceasing all food and liquid intake. For the first few days the patient will remain conscious and functional. They may feel a little hungry and thirsty, though will typically not experience pain or discomfort. Over a period of days, they will become progressively weaker and will start to sleep more. Lack of food and water causes dehydration, which eventually causes the internal organs to shut down. After several more days this results in a comatose state, and within another few days death occurs. The entire process typically takes between seven and ten days, though it can vary by a few days either way.

VSED is a natural process, and often gives the person a sense of empowerment and control as they prepare to let go of life. Unfortunately, most physicians are uncomfortable supporting people who have chosen this path, not because they disagree with it (though some inexplicably do), but because they are unfamiliar with it and don't know what would be required of them.

To be effective, the person must entirely eliminate all food and water. Even small amounts of water could prolong life for days or weeks. They should have all of their appropriate documents— including their Advanced Health Care Directive and DNR/POLST—completed and available.

A knowledgeable doctor should be intimately supporting the process with proper guidance and must be willing to prescribe medications (or collaborate closely with a hospice team) to ensure optimal comfort. Lip balms, lotions, sponge swabs, and misting sprays can help relieve symptoms of dehydration like dry lips, mucous membranes, and skin. A calm, loving, supportive environment is also crucial for this process to unfold gently and peacefully.

Most people undertaking VSED will benefit from having hospice care. This is especially true for the later part of the process when the person becomes extremely weak and slips into unconsciousness. Hospice will be able to provide medical equipment (such as an adjustable bed, commode, wheelchair, etc.), medications, nursing visits, and more.

It's also key to have 24 hour care available, at least for the final days of the process. This caregiving support team, which could include family members, friends, and private nurses or caregivers, should fully understand and support the decision.

You can learn more about VSED by watching this TED talk about one family's journey, and contacting us at Empowered Endings.

4. Medical Aid in Dying (MAiD)

In several U.S. jurisdictions, and many more internationally, it's legal for a competent adult with a terminal illness to receive a prescription for life-ending medication. This is often referred to as Death with Dignity or Medical Aid in Dying. These jurisdictions include California, Colorado, Oregon, New Mexico, Maine, New Jersey, Vermont, Washington State, Hawai'i and Washington, D.C.

While laws vary slightly state-to-state, most require that you are a resident of one of these jurisdictions to use this option. You must be 18 or over and competent to make medical decisions. Montana allows MAiD, though it utilizes a process that is different from the rest.

If this option is available in your area, you'd need to find a licensed Medical Doctor (MD or DO) to guide you through the process and ultimately prescribe the medication. Once obtained, the medication can be taken whenever you wish, and it is entirely your choice whether to take it at all. Many people with a terminal illness simply want to have the medication available, and don't have a definite plan for when or if they will use it. Some people with a terminal illness report that simply having the option of MAiD provides comfort and peace of mind.

There are many issues to consider regarding Medical Aid in Dying:

- Each state that allows MAiD has slight variations of the law, though there are certain requirements that apply in each state:
  - The patient must have a terminal condition with a life expectancy of six months or less
  - Two independent physicians—an Attending Physician and a Consulting Physician—must evaluate the patient and agree that they qualify
  - There is a mandatory waiting period following requests to the Attending Physician, ranging from 48 hours to 21 days
  - The patient must be able to self-ingest the medication by swallowing it or pushing it through a feeding or rectal tube
  - The patient must be competent and of sound mind; a cognitively impaired person is not able to request MAiD.
- It is highly advisable to engage a physician and team with experience in the process. Such a team will assure that all appropriate legal requirements are followed, and will be able to offer a higher level of support and understanding regarding the nuances of this process.
- Counseling for the patient, as well as the family and loved ones, is a critical factor in reducing the stress and anxiety associated with this process.
- Professional support by experienced providers at the time of ingestion, while not required by law, is highly recommended to prevent significant stress for the loved ones present.
- Bereavement support, specific to Medical Aid in Dying, after death occurs is another important protective factor in reducing the potential for trauma and complex grief in the loved ones left behind.

We hope this discussion of the various End of Life options has helped increase your awareness of some of the ways life can end. Our goal is to ensure that people have the information and support they need to live with joy and comfort, and die with peace and dignity. It's not always comfortable or enjoyable to talk about dying, but ignoring the topic too often results in angst and suffering that can largely be avoided.

4 where will you experience your end of life journey?

1. At Home

Over eighty percent of people in the U.S. say they'd prefer to die in their own home. Unfortunately, only 30% of people actually die at home. More than 60% die in hospitals and nursing homes.

With appropriate support, it's perfectly safe and acceptable to die at home or in the home of a family member. Independent or Assisted Living Communities, which have become popular places for people to live as they age, are also considered "home." Many areas now have a variety of assisted living options—including board and care facilities, which are typically private homes converted to residential care homes that accommodate up to 6 residents.

There are many options for the type of care and support available for in-home End of Life care. Patients who spend their last days, weeks, or months in their homes will receive far fewer unwanted or inappropriate interventions than those at an inpatient facility. They also tend to feel more comfortable and dignified.

2. In a Hospital

The number of people dying in hospitals has decreased in recent years, but it still happens too often. Hospitals are designed for people to receive emergency and acute treatment. The expectation is that people will improve and return home, or be transferred to another location to die. Hospitals were not created to support peaceful, comfortable, and dignified deaths. When someone dies in the hospital, it's usually considered a "failure". The death often comes after multiple procedures, treatment, and attempts at resuscitation. This makes dying in hospitals a dramatic, and often traumatic, event, both for the person losing their life and the loved ones huddled together in grim waiting rooms and hallways.

Emergency Rooms and Intensive Care Units are not strangers to death. However, ER and ICU deaths are typically "bad deaths". Often, people are dying amidst a cacophony of alarms and panicked voices. They're attached to IV drips, strange machines, and catheters. The doctors, nurses, therapists, and others working day and night in the hospital can be heroes and warriors worthy of respect. But often, they are neither trained nor experienced in supporting and guiding people toward a peaceful and dignified death. Sadly, dignified deaths rarely happen in an ER or ICU.

Patients in hospitals, and their loved ones, need to be informed of the reality of the circumstances so they can evaluate and assess their options. Whenever possible, we should strive to allow patients and families to have the gift of death in a more tranquil and controlled setting than a hospital or nursing home. That location is ideally their own home, surrounded by the people they love, in the most peaceful, supported, and dignified manner possible.

3. In a Nursing Home

Even the fanciest, most expensive nursing homes are usually not where people want to live … or die. They can be isolating, profit-driven, and heavily focused on their rankings and measurements. This focus is often in direct conflict with enhancing the comfort and dignity of patients.

Loneliness and depression are rampant in nursing homes. Sometimes residents are forced to share a room with strangers. Understandably, these strangers may be very ill, moaning or crying out, or struggling to breathe. The nursing home staff is usually well meaning. But they're often unable or unwilling to truly meet the individual needs of each patient, and there are typically too few of them to provide appropriate supervision and care.

As in a hospital, staff members enter residents' rooms throughout the day and night to check vital signs, give medications, and carry out other aspects of their jobs. But when something is needed urgently—like help going to the bathroom, being cleaned, or receiving pain medication—residents often need to wait, sometimes for quite a while.

When a person nears the end of their life the most important things we can provide them are dignity, comfort, companionship and agency. Being in a nursing home makes it difficult to provide any of these.

If you or a loved one finds yourself being referred to a nursing home for a "higher level of care" than can be provided at home, think long and hard about the alternatives. Often with a bit of out-of-the-box thinking, care can be established at home that will provide the kind of safety, support, and therapies that would be received in a nursing home, but in a much more comfortable and dignified setting.

4. In an Inpatient Hospice Facility

An option that may be available in your area is an inpatient hospice unit. These units can be located in a hospital or nursing facility, though there are also freestanding hospice homes and facilities sprinkled throughout the country. Some are affiliated with a particular hospice company while others are independent "hospice homes" where people are cared for by a committed team of caregivers and nurses. In these independent facilities, outside hospice agencies are brought in to provide medical care.

When a person nears the end of their life the most important things we can provide them are dignity, comfort, companionship and agency.

The length of stay at an inpatient hospice unit or home can vary depending on the facility and the situation. Patients typically stay anywhere from a day to a week, though in some instances they can stay for several weeks, even until death occurs. These facilities provide around the clock care like a hospital. But that care is delivered by people who have training and experience in End of Life care.

The focus at a hospice facility is on making the patient more comfortable. The setting is typically more like a home than a hospital, and the staff is trained to support end of life situations.

Like everything else in healthcare, inpatient hospice facilities vary widely in their approach and their quality of care. It's critical to research the specific in-patient hospice units you're considering and, if possible, seek professional experts for guidance.

The costs of care at inpatient hospice facilities vary widely. Some are independent and require payment—at least for the room, board and personal care. Others are run by nonprofit organizations and require little or no payment.

5 who will provide your end of life care?

> For others the opportunity to improve or maintain their strength, mobility and nutrition status could dramatically improve their quality of life.

1. Hospice

Hospice care is a Medicare and insurance benefit that provides a team of people dedicated to caring for terminally ill patients while providing support and guidance for families and loved ones. When delivered appropriately and in the right circumstances, hospice care can be very beneficial for people in the final stages of life.

There are times, however, when hospice care alone can result in negative outcomes for the patient as well as for loved ones. When hospice care is selected with limited or inaccurate information and unclear expectations, there can be confusion and frustration, and actual harm can come to the patient. It's critical to enter into the relationship with a hospice provider with a full understanding of what they do and what they don't do.

Because hospice care is a benefit provided and paid for by Medicare, Medicaid, and private insurance, there are restrictions on who they can care for and what care can be provided. The primary qualification for admission to hospice care is a life-expectancy of less than six months, and two physicians are required to certify that they believe this to be the case.

Once a patient is enrolled in hospice, the hospice agency is responsible for providing all the healthcare that person requires, including medical care, medications, equipment, and support from an interdisciplinary team of care providers. Because of financial constraints, hospice agencies sometimes make decisions about care that are not in the patient and family's best interest. It's usually not that they don't care or understand what patients and families want. They simply can't, or won't, provide some of the services and treatments that would improve the patient and loved one's quality of life because of financial limitations.

Hospice provides nursing visits on a routine, scheduled basis (usually once a week); social worker visits; spiritual counselors; health aid visits (usually twice a week); some of the patient's medications; and medical equipment. Nurses are available for urgent visits. Some hospice agencies also give patients access to integrative therapies, like massage or music therapy.

Hospice typically doesn't provide services that are designed to improve a person's strength and mobility, like physical therapy, occupational therapy, and nutritional support. Patients in hospice are usually not allowed to undergo curative or palliative treatments like radiation therapy, chemotherapy, or immunotherapy. These limitations may not be important for some people, especially those who are truly in their final days of life. For others the opportunity to improve or maintain their strength, mobility and nutrition status could dramatically improve their quality of life.

Patients on hospice usually lose the relationship with the doctors who've been caring for them. Instead, patients are assigned a doctor that works with the hospice agency. This is often a physician who works for the hospice agency on a part-time basis, overseeing care from afar. They rarely see patients in person or communicate directly with the patient or family. They almost always coordinate through the nurses who do the actual in-person care.

In some instances the lack of direct physician involvement doesn't pose a significant problem, but for some patients and families it results in anxiety and distress. At the time of life when a person is reeling from the realization that their life may be ending soon, the presence of a caring, compassionate, and knowledgeable physician can make an enormous difference. The benefit to loved ones is possibly even more significant. Being heard and held by a caring, compassionate physician often relieves the fear and frustration many people experience while supporting their loved ones through an End of Life journey.

At Empowered Endings, we consider this lack of physician involvement in End of Life care to be a gap of great significance. The reason for this gap is that most physicians—especially specialists like oncologists, cardiologists, and neurologists—don't feel able to invest the time overseeing the care of patients in hospice. They also don't feel particularly comfortable or competent in this space. So when a patient enters hospice care the relationship with their treating physicians is usually severed, and it's likely that they will never meet another physician through the final days of their life. If you think this sounds like an incomplete and unfortunate model of care, we agree.

Another misconception some have about hospice care is the amount of support patients receive from nurses and care providers. Many expect that as death approaches, and certainly at the actual moment of death, a nurse will be present to provide support and guidance. Unfortunately, most of the time this does not happen. The mission of hospice is to address the comfort of the dying person and help the family learn to provide the necessary support. Unless the patient is experiencing distressing symptoms or significant challenges, it is unlikely that the hospice agency will dispatch a nurse to be present at the time of a patient's death.

We want to be clear that we fully support hospice care and believe hospice is a highly valuable service. There are many caring and compassionate people working in the field. However, we're aware that the quality of care varies greatly from one hospice company to another, and even from one nurse, social worker, and spiritual counselor to another. The End of Life experience is too important to be hit or miss. As we've said before, there are no "do-overs."

We've found that the increasing number of hospice care companies has resulted in intense competition to obtain patients. Aggressive sales and marketing tactics are employed and people are often misinformed or under-informed about what they'll receive after they sign up. We recommend having in-depth conversations with potential hospice providers, and have a list of questions ready.

2. Palliative Care Programs

At its heart, we believe that Palliative Care is just good medicine. It is a philosophy, as well as a model of care, that focuses on helping people achieve the best possible quality of life given their circumstances. Palliative Care should address the whole person, recognizing that optimal health and wellbeing requires attention to the physical, spiritual, and psychosocial aspects of each human being. Palliative Care addresses symptoms such as physical pain, nausea, shortness of breath and fatigue, while also addressing existential and emotional pain, which contribute as much or more to a person's suffering than physical pain. Palliative Care is designed to support patients and families in making complex decisions about their health care, whether it be to continue aggressive treatments or to stop treatment and focus on care that brings comfort. It's about the patient and what's best for them.

Palliative Care is appropriate for anyone experiencing symptoms from a serious or complex medical condition. There are no restrictions with respect to age, condition, or prognosis. It is valuable for patients with cancer, dementia, heart and lung disease, kidney or liver disease, neurological disease, or the frailty of old age. Anyone in any stage of a complex or chronic illness could benefit from a consultation, and possibly an ongoing relationship, with a palliative care doctor and team. The Palliative Care consultations should also focus on advanced life care exploration and planning.

Most insurance plans cover palliative care, though some plans may require a prior authorization. Some HMOs don't cover palliative care, but many do. In the near future, as the benefits of palliative care become more obvious (including the cost savings) we believe more insurance companies will not only cover palliative care visits, but might even require it for certain conditions.

Most hospitals now have palliative care teams that will consult on patients who have been admitted to the hospital, especially people who are very ill or who have had multiple hospitalizations. Anyone can request a palliative care consultation while in the hospital, though it will be up to the attending physician and the palliative care team to decide if it is warranted. In the hospital, the team usually consists of doctors, nurses and nurse practitioners, social workers, and spiritual counselors. They help patients and families understand the complexities of their situation, advise other doctors about optimal management of symptoms, and help formulate an appropriate plan for when the patient is discharged from the hospital. It's a valuable service.

For people who are not in the hospital, there are two options for obtaining palliative care services in the community. Some hospitals and health care systems have outpatient clinics where people can be seen and treated. Some communities also have palliative care programs where doctors or nurse practitioners visit patients in their homes or wherever they live at the time. This type of care can be extremely sensitive to the needs of patients and families, is convenient, and allows the providers to become familiar with the patient's circumstances.

They help patients and families understand the complexities of their situation.

Most of the time, palliative care physicians act as consultants. They don't take over the patient's primary care, but instead work in collaboration with other physicians and providers. A palliative care physician or nurse practitioner may visit on a monthly basis, or more frequently if the situation warrants.

The benefit of a community-based, in-home palliative care program is that it provides a doctor or nurse practitioner who will come to the home, help manage pain and other symptoms, hopefully address emotional and spiritual concerns, and help patients and families make decisions about their ongoing medical care. This still leaves a significant gap that patients and families need to figure out how to work through to get what they truly need.

Currently, Medicare and most health insurance plans pay for the physician visits. The services of nurses, social workers, spiritual counselors, and other providers are typically not paid for by Medicare and insurance companies, so they're not provided. If they are, it's often to a minimal and ineffective degree. We often hear from our patients that they were referred to a palliative care program, but they did not receive adequate communication or support, which is disappointing and frustrating for them.

The type of care the Empowered Endings team provides could be considered palliative care, but it is not limited or restricted by what Medicare, Medicaid or private insurance companies will authorize or cover.

3. Death Doulas

There is a new movement emerging in End of Life care—a type of End of Life care provider who helps patients and their loved ones navigate the process of living with a terminal illness and dying. These End of Life guides, sometimes called death doulas, death midwives, or death coaches, have specialized training in issues that often arise before, during, and after death. They walk alongside patients and loved ones to ensure that they're heard, held, and whole through the journey. They understand the dying process, and can help facilitate grieving and letting go. They may also bring spiritual support and facilitate discussions among the family about life enhancing options, legacy projects, comforting rituals at the time of death, different types of burials, and much more. At times a Death Doula will be actively engaged to offer comfort and provide guidance. Other times they may simply be present, holding space for whatever is happening.

The Empowered Endings model uniquely brings doctors and doulas together in partnership, providing the core nucleus for intimate and compassionate support of our patients and their loved ones. Our model is built upon decades of experience in End of Life and grief care, and it's a model that works.

4. Empowered Endings

The Empowered Endings Medical Group is a one-of-a-kind medical practice that combines the medical knowledge and abilities of emergency medicine, palliative care and hospice physicians with care coordination, support from doulas and social workers, and a team of holistic, integrative therapists. This unique structure allows us to provide the highest level of comfort and support to people facing complex and terminal illnesses.

Like hospice, we provide an interdisciplinary team approach to ensure the comfort of each patient and family. Unlike hospice, expert physicians and End of Life Doulas are intimately engaged in the care of each patient and family. Unlike hospice, there is no "qualification" required to receive care from Empowered Endings, and no services or treatments need to be discontinued when patients receive care from us.

We add value to the care of the patient by complementing other care and support services they may already be receiving. We provide as much or as little support as each patient and family requires and agrees to (and is willing to invest in). We are available to provide guidance and support at any time, day or night. We also provide an array of integrative therapies to improve the physical comfort, and enhance the quality of life, for our patients.

6 how can you manage pain and other distressing symptoms?

1. Pain and Symptom Management

Terminally ill patients often suffer distressing symptoms like pain, shortness of breath, nausea, anxiety, and poor sleep. Making small adjustments to their medication, or giving them other means of controlling their symptoms, can make a meaningful difference—sometimes completely changing their quality of life. Some patients are afraid of pain medication; concerned about becoming addicted or experiencing side effects. This leads them to avoid these medications at all costs. Some feel that "giving in" to pain is admitting defeat, so they refuse and suffer.

We're committed to helping people understand that pain medication, when used with appropriate guidance, careful monitoring, and ongoing adjustments, can be safe and effective. It's crucial to have an open mind and an experienced health care provider that's aware of the situation and can make the best recommendations for you.

Pain and symptom management is critical for maintaining an optimal quality of life when dealing with serious or terminal illness. Within the traditional healthcare system it can be challenging for physicians and other medical providers to get it right. It may require more frequent appointments and checking in with the patient and family often to see how they're responding to treatments. Too often, this doesn't happen, so patients struggle, families are scared and frustrated, and the quality of life, as well as the quality of death, suffers.

We are often contacted by patients who express that their quality of life is significantly impaired because of pain. Sometimes this is the primary factor that makes them seek out support for End of Life options such as Medical Aid in Dying or Voluntarily Stopping Eating and Drinking. We find that addressing their pain management from a holistic and compassionate perspective will often improve their experience of life, and allow them to live longer and better.

2. Life Enhancing Options

In our experience, the benefits of holistic, non-traditional therapies for people struggling with pain and other distressing symptoms can be enormous. Massage therapy, acupuncture, music therapy, aromatherapy, healing touch, Reiki, and cannabis therapy are a few of the options we've facilitated for our patients and their loved ones to bring more comfort and connection into their lives. The physical impact is clearly beneficial, while the emotional or spiritual benefits are equally valuable. Patients and loved ones going through the challenges of the End of Life journey are often so focused on the logistics of care that they neglect their less obvious needs.

3. Palliative Sedation

Sometimes simple pain management isn't enough to provide relief for intense pain or suffering related to the End of Life process. In these cases, physicians may opt to use medication to induce complete sedation or coma. This treatment is not considered a form of euthanasia, because the goal is not to hasten death. Instead, the goal is to control the symptoms of disease and relieve the suffering of the individual. This treatment is always authorized by a physician and is typically administered through an intravenous or subcutaneous catheter, though it can sometimes be accomplished with oral medications.

The goal is to control the symptoms of disease and relieve the suffering of the individual.

Palliative sedation can be used continuously until the End of Life, or in intervals that allow the patient to regain consciousness for brief periods of time. Palliative sedation is also used to create a more peaceful death in cases of terminal restlessness or when life support is terminated. For patients that have palliative sedation for longer periods of time, there may be concerns raised by loved ones about their inability to eat or drink. Based on the patient's wishes, this may be a benefit as it will naturally shorten life. Because this is effectively hastening death, some physicians may require feeding tubes or rectal catheters to administer fluids. It's important to find the right doctor for this procedure, and to ensure that you understand their approach to long- and short-term palliative sedation.

7 in closing

The End of Life can be scary. It's a chapter that we'll each experience only once. There's no way to practice it, and there are no do-overs.

Despite these truths, we've learned through firsthand experience that the End of Life doesn't have to be grim, fearful, or miserable. When we reach that time, we don't have to lose our agency and sense of control. In fact, with the right support and guidance, the End of Life can be a beautiful, harmonious, and dignified finale to a life well lived.

We've made providing that support and guidance our lives' missions. We imagine a world where everyone who choses to do so has access to the tranquil ending they hope for and deserve.

If you, or someone you love, would like to discuss their options, Empowered Endings is here to help in any way we can. Click here to book a free consultation.

8 about the authors

Dr. Bob Uslander, MD, has practiced medicine for 35 years. As an Emergency Physician for 25 years, Bob witnessed the gaps in our healthcare system firsthand. Over the years, his growing concern about patients' quality of life and ability to influence their own treatment drove him to transition to palliative and hospice care. Over the past ten years, his practice of Palliative and End of Life medicine has focused not just on the physical needs of his patients, but also on their emotional, intellectual, social, and spiritual needs. He is passionate about eliminating the fear that keeps people from experiencing peace and joy at any stage of life.

Elizabeth Uslander, MSW MTS, has refined her expertise as a Spiritual Counselor and Medical Social Worker through decades of education and experience supporting people through the challenges of life's major transitions. All too often she witnessed the obstacles the people she served encountered in their search for whole-person, trauma-informed, culturally-competent care. Elizabeth is motivated to ensure agency and dignity for all in hopes of creating a new paradigm of healthcare—one that allows for the needs of each person and their loved ones to be heard and honored. Her greatest gift is transforming the pain of grief into the possibility of life.

When Bob and Elizabeth met, they realized they had a shared responsibility to transform palliative, End of Life, and grief care for all, Empowered Endings was born.

Empowered Endings brings together Bob and Elizabeth's experience and vision with the skills and expertise of like-minded professionals in many fields. Our goal is to ensure that patients and their loved ones always have access to an End of Life experience where their decisions, goals, and dignity are honored: an empowered ending.