

WAVE WORKSHOP #1 ON FINISHING STRONG

By Chris Palmer

Tuesday, March 14, 2023

Make highly participatory and interactive

Our goal with this workshop is to help village members and participants with questions about aging, death, and dying and to brainstorm ideas for possible village programs on those topics.

I want this to be interactive and participatory, so I'll stop for questions and comments every five minutes.

I'll start by giving a quick overview of the topic because it's a broad subject with many facets. Then we'll end by talking about potential village programs.

Planning for the end of life need not be morbid or gloomy. On the contrary, it's wise and gratifying to do so if we want to die on our own terms and in line with our values and preferences.

From movies and television, we've become accustomed to seeing death as fast, simple, and pain-free. In reality, death is frequently slow, disturbing, smelly, disagreeable, and noisy. This reality begins to explain why people would rather not talk about death.

I had dinner recently with a good friend in his seventies. Towards the end of a delightful evening, I asked him how he was planning for the time in his life when he is frail from old age. My friend responded, "It's so depressing; I don't want to discuss it."

My message today is that we can benefit from discussing it.

Six years ago, when I first launched the Aging Well group at BMAV, I called it the "Aging, Dying, and Death" group, but Board members were apprehensive that potential members would be turned off by seeing the words "death" and "dying" on our website or in our newsletters.

So we changed the name to Aging Well, but we must all face the fact that we will die. The mortality rate is 100 percent.

Death and dying are taboo topics, so we don't discuss them and, therefore, often arrive at the end of our lives largely unprepared and vulnerable to not being treated in the way we want.

Before the 1950s, deaths were predominantly from accidents or acute diseases that typically killed people relatively quickly. Final illnesses didn't last long. Infections like pneumonia caused most deaths. There was only a small involvement from doctors and technology.

Today, in contrast, 80 to 90 percent of deaths are from chronic diseases, such as heart disease, stroke, cancer, or dementia, and are protracted, with doctors and medical technology highly involved.

Dying is mainly done by older people unless we die by accident, drug overdose, suicide, or violence. Those causes of death tend to happen in younger people.

Most of us in the modern world will die slowly in old age of chronic, incurable illnesses, and we don't know really know how to handle these painfully slow deaths, sometimes lasting years.

People too often die badly. They die in pain; they don't have the help of hospice or palliative care; they're in an intensive care unit with their hands tied down so that they can't rip out all the tubes and machines to which they're attached; and they can't speak because they're intubated for air.

The lack of honest communication between doctors and patients can lead to hospital overtreatment. As a result, futile, excessive, and even harmful clinical interventions can continue into the last days of life, making it impossible for patients to have good deaths.

A patient's goals, values, and priorities must be paramount in the final stage of life. Unfortunately, too many doctors think that longevity is all patients care about, but polls show that most people care more about the quality of their lives than the longevity of their lives.

QUESTIONS AND COMMENTS

Let's talk about what makes a good death.

As I've said, many people die badly—lonely, isolated, in pain and despair, or kept alive against their wishes. In contrast, a good death is marked by serenity, acceptance, love, comfort, a sense of completeness, and being surrounded by a loving family and friends.

The dying person has a chance to say goodbye and thank you and hear from those present how much the dying person's life meant to them. The room is full of loving exchanges, expressions of tenderness and gratitude, shared memories of a well-lived life, and perhaps even joyful reconciliations. The patient has extensive emotional support and the best possible hospice care.

Achieving a good death like that requires planning and preparation.

The mission of doctors is to cure disease and relieve suffering. But for older patients, trying to cure a disease can sometimes *increase* suffering. In this situation, doctors should follow the wishes of the patient. At some point, it makes sense to cease aggressive medical care and choose palliative care and hospice instead.

Author and surgeon Atul Gawande observes in his best-selling book *Being Mortal* that textbooks used in medical school contain almost nothing on aging, frailty, or dying. He writes that many doctors know little about the realities of decline and mortality, and they understand virtually nothing about what might matter most to a person as they near the end of their life.

I'm not arguing that ICUs are *never* appropriate for older patients. If a vigorous and vibrant 90-year-old gets pneumonia or a urinary tract infection (UTI), they may need a spell in the ICU, and such an intervention can add value to life. But for most 90-year-olds, going into an ICU is often associated with a prolonged and miserable death.

CPR (cardiopulmonary resuscitation) is an effort by doctors and nurses to revive a patient after they have stopped breathing or their heart has stopped. They typically use powerful pushes on the chest together with shocking the heart with a defibrillator.

This makes a lot of sense on a strong person, but when CPR is applied to the frail old and the terminally ill, it can be futile and harmful because ribs get broken and the survival rates are low.

Providing harsh, aggressive treatments, like CPR, to older, terminally ill patients usually makes little sense, yet it still goes on. Interestingly, however, most doctors ask not to be treated that way themselves. Ironically, when planning their own end-of-life, doctors know when to stop pursuing longevity and seek a dignified, peaceful, and gentle death.

QUESTIONS AND COMMENTS

Let's talk about living well so as to die well.

The quality of our dying is shaped by how we live. As nurse and author Sallie Tisdale writes in her book *Advice for Future Corpses*, "Our lives as we live them day by day create the person we will be at the moment of death...With every passing day, we create the kind of death we will have."

There's much more to say about living well so as to die well, but time is short, so let me just make an observation about villages. Villages help people live well and thus help them eventually die well.

Joining a village is a way of gaining a "tribe," enriching our social life, and developing friendships. Many studies have shown that greater social relationships lead to a significant reduction in early death.

If we want a good death, we must lead a good life. To lead a good life, we should build relationships, assist others, and work on meaningful projects and causes. Living well helps us to die well.

QUESTIONS AND COMMENTS

Let's talk about death cleaning and decluttering.

It's important not to burden our loved ones with a big mess when we die. It is inconsiderate, for example, to leave our house or apartment cluttered with an enormous collection of possessions that we were too distracted or disorganized to weed out ourselves.

Death cleaning is sorting through and reducing all our stuff before we die rather than leaving countless possessions to children or other loved ones to sort out. How selfless to die with our attic, garage, basement, bookshelves, and closets all organized and cleared of junk. Otherwise, our children face the arduous and time-consuming chore of de-junking.

The more we can death clean, the easier it is for our loved ones to grieve freely and fully without being overwhelmed with all that must be done when someone dies.

QUESTIONS AND COMMENTS

Let's talk about advance care planning and the importance of talking with our loved ones about our wishes at the end of life and how we want to be treated.

There are several reasons we are so tongue-tied when it comes to death and dying: Parents don't want to cause their children anxiety and discomfort; children are reluctant to raise such an intimate topic with their parents for fear of somehow tempting the gods to bring it about; and doctors are taciturn on the subject because for them death signifies they have failed to save their patient.

But this lack of conversation leads to adverse outcomes for everyone. Conversations about death and dying must become routine if we are going to make it easier for people to achieve peaceful and good deaths.

Advance care planning includes completing an advance directive, deciding the treatments we would want or not want, deciding on a health care agent, and sharing our values and preferences with loved ones and our doctors.

An advance directive allows a patient to choose the type of medical care they wish to receive at the end of life when they can no longer speak for themselves.

However, advance directives are of limited use because the medical issues are often much more complicated and nuanced than the oversimplified advance directive anticipated.

Nevertheless, everyone should complete an advance directive because they can serve to encourage ongoing conversations with loved ones about what we want at the end-of-life, and this can then help our health care agent represent our views more accurately when we can no longer speak for ourselves and hard decisions have to be made.

The key is to use our advance directive as a starting point for an ongoing conversation with our loved ones about how we want to achieve a good death.

QUESTIONS AND COMMENTS

Let's talk about legacy letters, ethical wills, and memoirs. All these are ways of letting our loved ones know what is deep in our hearts.

The sting of death diminishes when we leave good works behind and live on in the lives of our loved ones and family.

Legacy letters, ethical wills, and memoirs reflect our values, wisdom, and deepest thoughts. They can strengthen family bonds, even after we die.

At the end of life, a dying person wants to feel their life matters and that their life is somehow complete. No one wants open loops and unfinished business—issues unresolved, projects unfinished, or love unexpressed.

People also want to be able to give a coherent and compelling answer to the questions, What did my life mean? Did my life matter?

One way to answer these profound questions is to tell stories about our lives that bring coherence and meaning to the events and activities that fill our lives and then put those stories into writing or a recording.

This allows us to convey our memories, stories, and wisdom to future generations. In addition, it means discovering what it is about ourselves that we value and think is worth preserving.

A legacy is built through conversations with loved ones, storytelling, modeling admirable behavior, and interactions with others.

It is also built through putting in writing—in the form of legacy letters, ethical wills, and memoirs—our head-earned life lessons.

Business strategist Peter Stropole wrote, “Legacy is not leaving something *for* people. It’s leaving something *in* people.” And psychologist Erik Erikson wrote, “I am what survives me.”

We each want to create a meaningful legacy that will survive us and be our gift to the future we will not see. We want our memory to be for a blessing.

We want to leave more than just money and possessions. We want to enlarge the lives of others who survive us. Creating a legacy letter, an ethical will, and a memoir are ways to do that.

QUESTIONS AND COMMENTS

Let’s talk about caregivers, a neglected group of people, usually unpaid women, which number by the millions.

A caregiver gives care to someone who needs help. The person needing help may need assistance because of an illness, surgery, frailty, or other reasons.

Over 40 million adults in the U.S. are caregivers—that’s about one in four adults. They manage the physical, emotional, and social needs of suffering loved ones and are vastly under-appreciated.

The plight of caregivers is a major problem in this country that will only worsen as the baby boomers swell the ranks of the elderly and frail.

QUESTIONS AND COMMENTS

END WORKSHOP #1 HERE

[IN THE NEXT WORKSHOPS ON MAY 4 AND JUNE 8, I'LL TALK ABOUT PALLIATIVE CARE, HOSPICE CARE, DEATH DOULAS, MAID, VSED, THE RIGHT TO DIE, WHAT TO DO WITH THE BODY, MEMORIAL SERVICES, EULOGIES, OBITUARIES, GRIEF, AND MOURNING. NOW GO TO PAGE 10]

Let's talk about palliative care, hospice, and death doulas. As the end of life approaches, they can all be extremely helpful.

As life winds down, we need to rely more on gentler medical interventions, or just comfort care with little intervention, to support a good quality of life.

Palliative care relieves the symptoms and stress of a serious illness and improves the quality of life for both patient and family. It can be provided to patients at the same time as curative treatment.

Palliative care focuses on the whole person and their families and is rooted in kindness, respect, and compassion. It encourages patients to be fully in charge of their own care and, with input from doctors, make decisions consistent with the patient's values and preferences.

Hospice is a philosophy of care that uses palliative care principles with terminally ill patients. It emphasizes patient comfort rather than cure.

Hospice care relieves suffering, optimizes quality of life, and helps patients live well until they die. It can help people live longer with less stress and anxiety and more comfort.

In the U.S., not-for-profit hospice care is the gold standard for end-of-life care. It is not a place or an organization but a model of care that focuses on gently comforting a terminally ill person.

Hospice is not "giving up" and does not make patients die more quickly than they otherwise would have. In fact, the opposite can occur. Patients often improve and live longer in hospice because of better pain management and overall care. Hospice is not a fast track to death. The patient is not giving up on life. They are simply choosing a smoother, gentler ride for the journey and living the best life until they die.

Unfortunately, most people don't receive hospice care until the final weeks or even days of life, missing out on months of helpful care and quality time.

But while hospice teams are impressive, the fact remains that patients on hospice are on their own most of the time, and so there is an abundance of work left for friends and loved ones to do.

The hospice nurse will teach caregivers how to administer, for example, morphine if it's needed, but actually administering morphine and other medications, keeping the patient clean, changing bed sheets, shifting the patient's body so they don't get bed sores, and a range of other menial, tedious, and burdensome tasks is left for the family to do.

If affordable, hiring a nursing or home health aide probably makes sense to help reduce the daily work burden on caregivers.

Many people are familiar with birth doulas, but “doula” is also used to describe people who help patients and families at the end of life. They are called death doulas, death midwives, end-of-life doulas, or end-of-life workers and offer non-medical help. If affordable, they are often a wonderful addition to hospice care because they can spend extensive time with the patient, coaching them, helping them, comforting them, listening to them, and keeping them comfortable and clean.

Death doulas are an excellent supplement to hospice care because they provide the one thing hospice has a limited supply of, and that is spending virtually unlimited time with the families and patients. Death doulas can be there at the time of death as well as before and afterward.

Palliative care, hospice, and death doulas can be a godsend to patients seeking help dealing with severe illnesses and other potential end-of-life issues.

QUESTIONS AND COMMENTS

Let's discuss the right to die, medical-aid-in-dying (or MAID), and voluntarily stopping eating and drinking (or VSED). These are all ways to give patients more agency at the end of life, but they are controversial issues.

People are living longer but also tend to be sick longer before dying. Thus patients face the issue of whether to prolong life as long as possible and risk experiencing intolerable suffering and deterioration, or find ways to die peacefully and gracefully. The “right to die” means that each individual should have the right to choose a peaceful, dignified death consistent with their values.

We should each be free to shape and design how our lives will be completed when faced with a future riven with pain, suffering, and indignities. We should have sovereignty over our bodies—the right to control our bodies. The right-to-die is a moral principle founded on the belief that a patient near death is entitled to end their life intentionally and deliberately, with dignity and support.

Episcopal priest and death expert John Abraham says, “The right to hasten one's death is the next great civil right” to fight for. He thinks it should be lawful for a competent person suffering unbearably to end their life deliberately and intentionally with peace and dignity.

Terminally ill patients, especially older ones, should be able to use drugs and other means (such as voluntarily stopping eating and drinking) to access a peaceful death and to avoid suffering pain, agitation, delirium, air hunger, nausea, and other symptoms.

The ways of hastening death in the face of intractable and unbearable suffering include:

1. Withholding and withdrawing unwanted life-sustaining treatments
2. Voluntarily stopping eating and drinking (VSED)
3. Palliative or terminal sedation (what used to be called “barbiturate sedation”)
4. Lethal medication, including medical-aid-in-dying (MAID) and euthanasia.

Euthanasia comes from the Greek and means literally “a good death.” It refers to an illegal process (at least in the U.S.) in which a patient’s life is ended by a doctor using lethal drugs, like a veterinarian putting a dog “to sleep.”

MAID, in contrast, is when a doctor writes a lethal prescription for a patient with a terminal disease to end their life *by their own hand*. The patient is in charge and has autonomy.

I am not recommending that patients with debilitating terminal illnesses all hasten their deaths through VSED, MAID, or other means. That is up to each one of us and intensely personal.

QUESTIONS AND COMMENTS

END OF WORKSHOP #2

[IN THE THIRD AND FINAL WORKSHOP ON JUNE 8, I WILL DISCUSS WHAT TO DO WITH THE BODY, MEMORIAL SERVICES, EULOGIES, OBITUARIES, GRIEF, AND MOURNING.]

Once a person has died, the most immediate issue is what to do with the dead body and how to dispose of it respectfully and responsibly.

The investigative journalist Jessica Mifford took on the U.S. funeral industry in her best-selling book *The American Way of Death*. She bluntly accused “funeral men” of ripping off grieving families. She criticized funeral directors as predators, ruthless bilkers, and con artists who took advantage of distraught families by overcharging for funeral and embalming expenses.

Her book is a scathing rebuke of the funeral industry, which she accuses of avarice and profiting obscenely from dying and death at the expense of bereaved families.

Long before we die, it’s worth our time to visit a few funeral homes near us, talk to the director, assess our level of comfort with them, and do some preplanning. In other words, shop around. Ask neighbors for recommendations and Google “funeral homes” in your area.

A funeral director may be the worst person to provide a meaningful death ritual because they want us to spend as much as possible. On the other hand, an empathetic and honest funeral home director can be a godsend because they know so much about the most effective way to dispose of a body in a memorable and appropriate process that aligns with our values and preferences.

Embalming is not required by state or federal law, although some funeral homes will cunningly give the impression it is. Some funeral homes insist on embalming if the family wants to view the body.

Embalming delays decomposition and restores a lifelike appearance as though the person is sleeping rather than dead. However, the chemicals involved in embalming, such as formaldehyde, are highly poisonous and buried with the body, and thus will leak out into the surrounding area. Refrigeration also delays decomposition and is cheaper, less toxic, and less polluting than embalming.

Outer burial containers for caskets are not required by state or federal law. However, most cemeteries require an outer burial container, either a concrete grave liner or a vault, to stop the grave from collapsing and make mowing the grass on top of the grave difficult or impossible.

No casket or vault will preserve or “protect” the body from decay, decomposition, or the eventual entrance of water and earth. “Sealed” containers are more expensive but provide zero benefits to grieving families.

Home funerals, which allow families to care for their dead loved ones and all aspects of a funeral at home, were quite common in the U.S. until the 1930s. Family and friends retain custody and control of the body from death until final disposition.

Home funerals seek to return the care of the dead to their families. It is a movement to regain the lost skills and self-reliance of our forebears, and it is driven by a vision of creating more meaningful ways of honoring and caring for our dead in our own homes and communities.

The best environmental way to dispose of a dead body is through green or natural earth burial.

I’m happy to answer questions and tell you more about green burial, conservation burial, conventional burial, embalming, flame cremation, water cremation, alkaline hydrolysis, natural organic reduction, home funerals, and other means of disposing of dead bodies.

QUESTIONS AND COMMENTS

Let’s discuss ways to commemorate and celebrate a person’s life after they have died.

The primary purpose of a funeral or memorial service is to celebrate the deceased and comfort the living. The desires of the family and the dead person must both be considered.

It is appropriate for a dying person (or any person who may one day die) to plan their own funeral. Doing so is a generous gift to our loved ones, who will appreciate the help and feel good that they are giving us what we want.

QUESTIONS AND COMMENTS

Now, let's turn to grief and mourning: what it is, how to deal with it, and why it is often incredibly and unbearably painful.

Coming to terms with death and the end of life can be intense, tough, and challenging. Grief is the internal experience of loss, while mourning is its outward expression. Together they are called bereavement.

Grief is what we think and feel on the inside when someone we love dies, including loneliness, panic, pain, yearning, and anxiety. Mourning is the outward expression of our grief, including crying, journaling, and writing letters. Mourning is often challenging because people tend to be uneasy with outward expressions of grief.

Grief and love are inextricably tied together. To live well means to love. To love means to feel gratitude and profound appreciation for another and thus to suffer one day from the piercing agony of grief. Grief is love's fury at the damage inflicted on us by death.

All who love deeply must, at some point, bear the pain of loss. Suffering is the natural response to loss. Author Barbara Coombs Lee writes, "Such suffering can be one of the most profound experiences in a fully-lived life." Author and death-care expert Barbara Karnes, RN, says it is essential to accept grief and the hurt and pain within us and not try to push it away, hide it, or deny it.

QUESTIONS AND COMMENTS

I'm pivoting now to the second goal of this workshop: developing programs on aging, death, and dying in villages.

I was reminded how useful it can be to brainstorm together when I talked recently with Fran Lorenzi, a member of The Village in Howard. Fran suggested a great idea that had never occurred to me: developing a multigenerational program based on aging, death, and dying issues.

My wife Gail and I have created the \$5,000 Finishing Strong Award in WAVE to incentivize villages to develop programs in this area. The goals of the award are to encourage more conversations and discussions about end-of-life issues and create programs that village participants and members feel directly benefit them.

We hope the Finishing Strong Award will encourage proposals with replicable and scaleable ideas that other villages can readily copy or adapt. And, of course, WAVE welcomes submissions from villages of all sizes.

Many people thirst for information about aging, death, and dying. Despite living in a death-denying society, they welcome having serious conversations on these sensitive topics.

Many books, videos, websites, and other information sources exist on aging, death, and dying. However, what seems to be missing is tangible support for individuals. This is where the villages can be so powerful. They are structured to help and support older people in their communities.

Villages might take various approaches to develop programs in this area. For example, they might use workshops, outside speakers and consultants, one-on-one coaching, buddy systems, blogs, handouts, retreats, or other tools or mechanisms to reach out to their members and participants.

I'll send you a background paper on what I did to create and lead the aging, dying, and death group at BMAV.

This BMAV group is invaluable because of the learning that occurs about aging, death, and dying and because it helps village members get to know each other and bond. The mood and tone of the meetings are typically upbeat and fun. There is camaraderie, humor, and curiosity.

The group is as much about community and connection as it is about aging, death, and dying. By coming together in monthly meetings where members discuss important matters to each of us, members make a genuine connection to others and a sense of meaning, togetherness, and community.

It truly exemplifies the goals of the village movement.

QUESTIONS AND COMMENTS

Afterward, send attendees the following handouts:

- Hospice handout
- Handout on creating an aging well group in BMAV
- Example of my monthly letter
- Legacy letter handout
- Green burial handout
- Death and dying letters