What is End of Life?

It seems to me that we really don't have an accurate definition of this.

I, among others, propose that dying, or end of life, be treated as its own distinct life course stage. For us Americans, the end-of-life period is longer than it has ever been. A hundred years ago, people died suddenly or soon after becoming sick. These days, that is often the case with COVID-19. But for most other leading causes of death among older adults — cancer, heart disease, chronic obstructive pulmonary disorder — there can be a long time period between becoming sick and dying.

By thinking about the end-of-life stage as something that we may have some influence over we might demystify it.

Perhaps the end of life is like any other life stage, with developmental tasks to ensure smooth transitions. Just as we learn, as children, how to be a teenager and then how to be an adult, maybe we need to learn how to prepare for the end-of-life stage. Currently, the recognized main stages are infancy, childhood, adolescence, young adulthood, midlife and old age. Even though these stages make sense to us now, some of them are actually pretty new - the idea of adolescence didn't exist until the very early twentieth century. Likewise, midlife, or middle age, is a fairly modern construction.

It is ageist to say that old age equals death. Old age may be a powerful risk factors for death, but about twenty-five percent of all people who die each year are under age sixty-five. My father died at age 96 and had his wits about him until the day before his death.

Let us consider the biological or legal markers for life stages: For example, adolescence generally correlates to puberty; In most states, people are legally considered adults at age eighteen. Old age is typically thought to start at sixty-five when most people become eligible for Medicare and Social Security. Yet the starting point for the end of life is not clear, and we cannot categorically state when that stage starts because the trajectory is unknown.

Typically listed components of good death

- Management of physical and psychological pain and distress
- Collective decision-making over treatment
- Preparation for death
- Completion of unfinished business
- A sense of usefulness as a social being
- Unique and empathic treatment of the dying
- Dying with dignity
- Not dying alone

Strong emphasis on the importanc of an **awareness of dying** and **active autonomous reciprocity** between patients and caregivers

Once people start developing major chronic illnesses (whether they expect to continue living for one year or four years or ten years), they might well consider how they want to live during that stage of life. It would be best if we were to encourage them to discuss the topic with family members, embrace it and take the steps that one needs to take in order to have that stage of life be as pain-free and peaceful as possible. Let us prepare for, rather than avoid thinking about, the inevitable.

What might be some of the developmental tasks for this stage of life? How about discussing funeral rights, plans, and other options for the disposition of the body. Discuss how those left behind will be equipped financially, and how they will handle household tasks in your absence. People can begin and continue to modify advance care planning (Choice and Dignity offers two programs to help with this.) Doing these tasks will help demystify the final stage.

Accomplishing these tasks will enable one to have a more satisfactory end-of-life period that accords with one's wishes, and it can make the end-of-life period easier for lovedones who are not left guessing about their loved one's values, fears, and preferences.

- John Abraham

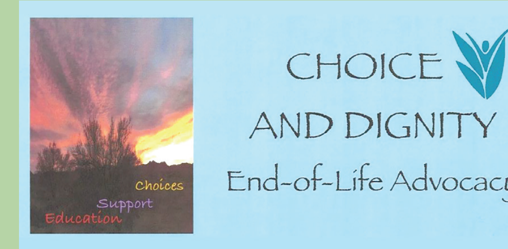
Dear friend of Choice and Dignity, Inc.,
At our board of directors meeting of August 3, we concluded that we really need your help.

1. We need someone to take over putting together our quarterly newsletter! (And for this September issue we plan to only post it online, and mail it only to the few people who are on our phone tree. We welcome your feedback about it being online.)

2. We need new board members! Please seriously consider serving in that capacity.

3. We need more funds! Recently we agreed to try using Flipcause to better keep you informed. It costs $90 per month and we need help for that among other things. Thank you.

More than one-third of Death with Dignity groups' income comes from bequests – generous members who want to help others after they are gone.
Please add us to your legacy.
We certainly would appreciate your putting us in your will:
Tax ID# EIN- 84-4667788
Choice and Dignity, Inc.
PO Box 86886, Tucson, Arizona 85754
Donations can easily be made on our website.



Choice and Dignity, Inc.

End-of-Life Advocacy
PO Box 86886 • Tucson, AZ 85754
Newsletter - Fifth Edition, September 2021
800-811-4112
Email: ChoiceDignity2021@gmail.com • www.ChoiceAndDignity.org

Please share this with a friend or neighbor to help spread the word.

Improving Care at the End of Life: Five Possibilities

We all face the difficult prospect of a parent or loved one suffering from an illness that ultimately leads to death. When that time comes, we want to ease their physical and emotional pain, respect their wishes, and allow them to die with dignity — the same things most will want for themselves.

The way that Americans die has changed but, unfortunately, our medical system hasn't kept up. The system was designed at a time when death was often sudden or declines in health were relatively rapid. These days it is much more common for people to live longer with multiple chronic conditions, and we have the technology to prolong life as death approaches. End-of-life care is fragmented, intensive, and costly — and patients' wishes are often lost due to poor communication. (For more about this, plan to attend Choice and Dignity's Advocacy Training!)

> ***The way that Americans die has changed but, unfortunately, our medical system hasn't kept up. The system was designed at a time when death was often sudden or declines in health were relatively rapid.***

As baby boomers continue to age, swelling the ranks of the elderly and those near death, how seriously ill people approaching the end of life are cared for must be reformed. Here are five possibilities for reform.

1) Train more clinicians in palliative care. Graduate medical education includes little training on the needs of patients in the last years or days of their lives. We need to create financial and professional incentives to expand the number of doctors, nurses, nurse practitioners, social workers, and other health care professionals who have the right training to effectively and compassionately provide end-of-life care.

2) Emphasize planning for the inevitable. We need to make creating an advance directive and speaking to loved ones about end-of-life care wishes as natural and commonplace as financial planning. Far too many care decisions are made by family members who are only guessing at the wishes of their loved ones. It's awkward, but necessary, to talk about death and dying. By integrating advanced care planning into what we already do in our daily lives, like using smartphones or making employee benefit decisions, we can encourage these much-needed conversations. Make Advance Directives standard nationally, not specific to each State.

3) Refine Medicare coverage. Two serious gaps in health insurance coverage threaten many people facing the end of life. Medicare does not provide coverage for social supports, like breaks for family caregivers, or for the coordination of care. Medicare policy should be changed to include benefits for those diagnosed with advanced illness that provide social supports and care coordination through a defined care team. Such coverage would encourage team-based organizations to meet the needs of patients. Medicare could test the integration of its hospice benefit into Medicare Advantage. Improving efficiency and delivery will help those who are seriously ill get the care they need — and help their caregivers deliver it — without jumping over hurdles and battling a bureaucracy not designed with their circumstances in mind.

4) Measure the effectiveness of end-of-life care. Only by understanding how well health care and social services support individuals at the ends of their lives can we understand, demand, and reward good performance by their caregivers. Therefore, we need to develop metrics that can provide accountability and transparency. In addition to measuring the quality of

POSSIBILITIES *continued on next page*

Possibilities

continued from previous page

care, these metrics must also measure patient preferences and families' experience as they care for their loved ones.

5) Get community input on better models of care. Addressing this urgent need will create inevitable disruptions in how health care is delivered. Leadership by policymakers and private sector leaders is required to improve end-of-life care, but so is a social consensus that such a change is needed. This can happen only at the local level. Some communities (Such as members of Choice and Dignity, Inc.) will rise to this challenge. Those that do so successfully should be held up as examples and the lessons they learn shared with others seeking to achieve the same ends.

I hope that health care policy leaders will tackle these problems head-on. Much more can be done to make sure that all Americans die according to their wishes and with dignity. By implementing the ideas outlined above, we can make important strides to that end.

- John Abraham

Caring for someone at home with terminal illness

This article from July 2021 is from the Association for Death Education and Counseling (ADEC).

Families caring for someone at home need better support with medication management.

When somebody is seriously ill and dying at home, managing their medications can be a difficult and complex task. This is made more difficult given that the care often needs to be given when patients and their families are tired and emotional. Family members are often assumed to be willing and able to support patients with their medication. However, little is known about what these tasks involve or how families cope with them.

In a study led by Professor Kristian Pollock from the University of Nottingham, a team of experts explored the views of patients and families managing medications in their homes. The study reports the outcomes of 21 interviews with bereaved family caregivers and 43 interviews with patients and current family caregivers.

The research, funded by the National Institute for Health Research (NIHR), found:

- More awareness is needed to understand the ways that managing medications add to the considerable burden of care and work that must be undertaken when someone is seriously ill and dying at home;

- Family caregivers are increasingly expected to undertake complex and technical medication tasks formerly carried out by professionals, but with little if any training, this supervision or support. This trend has been exacerbated by COVID-19;

- The work of managing medications is critical to enabling patients to remain at home at the end of life. The findings of the research have implications for practice and policy;

- Health care professionals will benefit from a greater understanding of the complexities of medications management undertaken by patients and families in order to identify and tailor the support they can provide;

- Substantial reduction in the complexity and bureaucracy of health and social care services is needed for them to be navigable for patients and families managing medications at the end of life;

- The lack of presence of Community Pharmacists in this research suggests there may be a greater role for them in supporting patients and families to manage medications at home.

Dr Eleanor Wilson, from the Nottingham Centre for the Advancement of Palliative and End of Life Care (NCARE) in the School of Health Sciences at the University of Nottingham, worked on the study. She said: "Our findings show that managing medications at the end of life can be considerable 'work'; Including practical and physical work of organizing, ordering and collecting medications, the emotional work of supporting someone to take their medication and the knowledge-based work of understanding what medications are for, when they should be taken and what side effects they may cause.

This medicines' 'work' often needs to be done when patients and families are tired, upset and under pressure, so health professionals need to be alert to how much they are asking families to do at this time."

Life's Decisions

Most of this is from an article by Andrew Krosofsky on the Greenmatters website.

'I see a good death as one where the patient can express what they feel, what they fear, where they find peace, and where the family is willing to talk about the journey of death'

As much as you try to live a healthy, vegan, low-impact lifestyle, the common methods of body disposal, like traditional burial or cremation, are not going to be nearly as eco-friendly as your choices were in life. Luckily, there are plenty of ways to "fight the good fight" even after you have shuffled off this mortal coil.

Many of these natural interment methods have risen to prominence in recent years and are becoming much more accepted by society. Green burials also tend to be more affordable than the average traditional burial or cremation. Here are some of the best ways to ensure that your remains are buried as eco-friendly.

If you think that cremation is the best way to go, you are sorely mistaken. A single cremation uses about as much gas and electricity as a 500-mile road trip. This process also ends up emitting approximately 250 pounds of carbon dioxide.

Traditional burial isn't much better. It might actually be worse, in fact, at least from an environmental perspective. Coffin burials use an estimated 100,000 tons of steel and 1.5 million tons of concrete annually. In addition, some 77,000 trees used for wood and 4.3 million gallons of embalming fluid are also used each year in the U.S.

The breakdown of these materials, specifically the carcinogenic embalming fluids, can leach into the ground and pollute the earth. These are not the best methods for disposing of a body.

Here are more eco-friendly ways of returning your body to the earth.

Mushrooms and other types of mold, bacteria, and fungi love to feast on decomposing flesh. Unfortunately, the formaldehyde and other embalming fluids commonly used in traditional burials prohibit this from happening. But those chemicals can be eliminated.

The mushroom burial suit is a black shroud, lined with special mushroom spores that are meant to be worn after a person dies. The mushrooms are trained to devour dead human tissue, thereby recycling our bodies rather than using them to further pollute the earth.

Similarly, the Living Cocoon is a mushroom-based coffin that enriches the earth as it decomposes.

In the early 1970s, anthropologists wanted to study how bodies decompose naturally. They used cadavers, which were placed on a "farm" in a wide array of decomposition scenarios. Bodies were placed in swamps, in the grass, in the sun, in the trash. They were eaten by crows, maggots, and vultures. And now you too can be a part of the adventure after you die by donating your body to a Body Farm!

Texas State University has one of the largest body farms in the country. Here, students, scientists, and would-be detectives use dead bodies to study criminal science, microbes, and thanatology. This option will save money, enhance scientific research, and return your body to the natural world in a natural way.

Green burials are just more variations on the theme of organic burials. In this instance, the graves are dug by hand, and the coffins are biodegradable, made of either wicker or an unbleached burial shroud. There is no cement plot reclaiming your body. Many green burial grounds can also act as wildlife refuges, making them important for conservation. Such plots tend to be far cheaper than those at conventional graveyards.

In a sky burial, people take the bodies of their deceased to a place where local vultures come to feed. This allows the remains to be repurposed back into the food chain in a very visceral way. And while the application of this ritual is based on the belief that the dead will then return to the universe without any of their earthly baggage, it's also quite practical in a place where digging a grave is particularly difficult.

Aquamation is a unique burial method. The body is placed in a stainless-steel vessel filled with a solution of 95 percent water and 5 percent potassium hydroxide or sodium hydroxide. This mixture, combined with alkaline waters and temperatures around 350 degrees Fahrenheit, causes the body to dissolve. All that's left is a partial skeleton, which is ground up into a white pearl powder and given to the person's loved ones. And it only emits about a fifth of the carbon dioxide belched out by traditional cremation.