

Appendix I

Three Letters Describing My Desired End of Life

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#1: A LETTER TO MY FAMILY ABOUT MY END-OF-LIFE WISHES

SUMMARY OF LETTER

I do not want my death to be protracted or lingering, especially if I am bed-bound and cognitively impaired. The quality of my life is more important to me than its length.

Highly intensive medical technology for older people is rarely helpful and often only causes suffering. I don't want to end up hooked to tubes and machines. I want to be home with my loved ones or in an inpatient hospice like Casey House if it is too challenging to take care of me at home.

As I enter the last phase of my life, the following are important to me: being able to talk with all of you, being mentally alert and competent, preserving my quality of life, having autonomy and independence, being comfortable and free of pain, leaving good memories for all of you, dying quickly to avoid wasteful and expensive care.

I love so much about my life—being active, spending time with grandkids, writing, giving talks, and volunteering—that if none of these activities were possible for me to enjoy anymore, I would want to go out peacefully without a lot of heroics. I want my doctor to refer me to hospice as soon as I am eligible.

If I'm severely compromised (for example, by dementia or other illness) and unlikely to regain my ability to recognize loved ones, I'd consider my life over and want you to carry out my wishes for a peaceful death. Please do not work to prolong my life.

I believe if I have an irreversible illness or intractable pain, I have the right to end my life in any way I choose—a right to death with dignity.

I support terminal sedation, medical-aid-in-dying (MAID), and voluntarily stopping eating and drinking (VSED). I want access to MAID medications (if legal) so I have the option of taking a lethal dose of medicine. I do not want my life prolonged artificially after it has ceased to be the life I want.

Dear Gail, Kim, Sujay, Tina, CJ, Jenny, and Chase,

Every day, I'm so grateful we are all alive and healthy, and I hope we stay that way for a very long time!

As you know, I feel strongly about the importance of discussing how we want to be treated at the end of our lives and how the time to have that discussion is sooner rather than later. As the old maxim goes, we should repair the roof when the sun is shining.

So, this letter is my way of getting the discussion started! My personal mission statement outlines my views on death and dying, and this letter supplements what I wrote there.

The nonprofit organization Compassion and Choices, as well as the outstanding books *Finish Strong: Putting Your Priorities First at Life's End* by Barbara Coombs Lee and *The Art of Dying Well: A Practical Guide to a Good End of Life* by Katy Butler, have informed this letter and I am grateful to them.

Health Care Agents

Gail is my health care agent (or proxy) and will speak for me if I cannot. If Gail dies before I do or is incapacitated and unable to act as my health care agent, then Kim, Tina, and Jen will be my health care agents.

One of my goals with this letter is to give you the confidence to make hard decisions on my behalf if you must. In giving you this confidence, I also hope to provide you with peace of mind because you will know that you honored my wishes and that whatever decisions you made had my blessing.

Valuing the Time We Have Left

You might be thinking, “Why do we have to think about all this morbid, gloomy stuff?” My answer is that I love being alive, and it is sad to think about life ending, but knowing my life will end and facing that fact forthrightly doesn’t make me feel morbid or gloomy. Instead, it makes me value the time I have left and strengthens my determination to protect its quality.

We plan for vacations to get the most out of them. We plan for retirement. We plan for our children to attend college. We plan for all the important events and developments in our lives. And yet, when it comes to the end of our lives, we tend not to think or talk about it. I believe this is a mistake.

Many Older People Don't Get What They Want

Most people want to stay in their homes towards the end of their lives. They want as much independence as possible and to be surrounded by friends and family. They want gentle and meaningful interactions with loved ones and to be free of suffering and pain.

But that isn't what most people get because they haven't prepared and planned ahead of time. Too many people begin to consider these questions only when a health crisis hits, which is a terrible time to make crucial decisions, such as whether you want CPR, surgery, or mechanical ventilation.

What Is a Good Death?

One of my life goals is to usher all of you gently through the process of my death so that, in retrospect, it is a positive, memorable, and loving experience for you.

I don't want you to suffer by watching me suffer. I do not want to be seen and remembered in a sad, pitiful state. I want to die *before* becoming a stranger to you through the cruel ravages of old age, particularly if I become demented.

I want my death to be peaceful and gentle, but I also want my exit from this world to be a meaningful, memorable, and even sacred time for all of you. So many survivors are traumatized by what they witness as their loved one dies in an ICU, with doctors frantically attempting to keep the dying patient alive for another few hours or days. I don't want you to be traumatized by my death.

When I approach the end of my life, which may be many years away, I want to ensure that my values and preferences are respected and honored so that I can achieve a good death, one free of pain, suffering, regrets, unfinished projects, and ineffective medical treatments, and, at the same time, one full of love, peace, and gentleness.

I want to make the most of those last few weeks and months of my life and have the opportunity to say goodbye to each of you.

I aim to “walk through the valley of the shadow of death” with stoicism and courage, bringing cheer and comfort to those around me.

My Death

My healthy lifestyle (and major surgeries for prostate cancer and heart disease) decrease the chance of my premature death but increase the likelihood of death by a chronic and painful illness like congestive heart failure.

A slow death in this way is often terrible. A peaceful and gentle death requires a strategy or plan. Leaving it to chance will likely result in prolonged suffering and futile over-medicalization that only wastes money and depletes precious resources. I want us all to be able to talk about it. Dying should not be a taboo topic.

Mommy/Gail and I disagree about whether my mother’s four years in a nursing home were what she would have desired. I am pained by the memories of her loss of functionality and dignity, and I am clear that I want to prevent what happened to her from happening to me.

I do not want my death to be protracted or lingering, especially if I am bed-bound and cognitively impaired. *The quality of my life is far more important to me than its length.*

My Motivation for Writing This Letter

In addition to letting you know my wishes for the end of my life, I hope this letter will help *you* achieve good deaths when your lives end, hopefully many years after I die.

My goal is to set an example of how to have a good death, and fulfilling this goal will imbue my life with meaning and purpose until my last breath.

I am conscious that how I die will set an example to all of you who come after me. I hope you will write a letter similar to this to your loved ones when you are still in the prime of your lives. It would supplement your advance directive—as this letter does mine.

We each need to spell out what we want so we have some control over what happens to us. Death is unavoidable and can happen at any time. Better to approach it intentionally than haphazardly.

Make Sure My Doctors are Candid and Honest with Me

I have written the attached letter to my doctor telling him how I want to be treated. Still, for many reasons, doctors are often reluctant to tell their patients that cures will no longer work and that it's time for comfort care, hospice, and efforts to maintain a high quality of life as long as possible.

Please make sure my doctors are candid with you and me and tell all of us the truth about the effectiveness of additional treatments. I always want to know the truth about my condition, treatment options, and the effectiveness of treatments. I don't want to be deceived or misled.

Inflicting Overmedicalization on Older People

As long as I am thriving and vibrant, I welcome care that will restore my health and help me retain a high quality of life.

Knowing that highly intensive medical technology for people in their 80s and 90s often doesn't work and causes undue suffering, I don't want to end up hooked to tubes and machines. I

don't want to be isolated in an ICU, confused, ventilated, intubated, and in pain. I want to be home with my loved ones (all of you!) or in an inpatient hospice like Casey House if it proves too challenging to take care of me at home.

I do not want to live as long as possible, regardless of my quality of life. If the prognosis is grave, my physical state is dire, and there is little chance that I will ever regain mental or physical function, I want to be allowed to die peacefully and as quickly as possible.

Being assigned to an ICU and hooked up to multiple machines would be worse than death for me. The pain, discomfort, isolation, lack of autonomy, and hopelessness would be unbearable and torturous.

At the end of my life, I do not want mechanical breathing and artificial ventilation, tracheotomy, CPR, artificial nutrition and hydration (through a nasogastric tube or a PEG tube), hospital intensive care, electroshocks to my heart, medications to stimulate heart function, dialysis, chemotherapy or radiation therapy, or surgery.

There may be other machines, drugs, or approaches yet to be invented that would, if used on my body at the end of life, add a few hours or days of diminished existence. Please know that I do not want any such "assistance."

Instead, I want the end of my life to be driven by quality-of-life issues and palliative care rather than invasive and painful medical care, especially if the prognosis is poor.

If a hospital or any health care person associated with them or involved in my care intentionally ignores my advance directive and dementia coda and overmedicalizes me contrary to my wishes, please take legal action against the institutions and the persons who disregarded my wishes so we can set a legal precedent (based on the "wrongful prolongation of life") that others in the future must respect and follow advance directives.

Lawsuits in Georgia, Alaska, and elsewhere have resulted in large monetary settlements and, more importantly, put everyone involved in health care on notice that they should pay attention to advance directives.

As I Enter the Last Phase of My Life

As I enter the last phase of my life, the following are important to me: being able to talk with all of you, being mentally alert and competent, preserving my quality of life, having autonomy and independence, being comfortable and free of pain, leaving good memories for all of you, dying quickly rather than lingering in agony, and avoiding wasteful and expensive care.

Each of you knows me and can see what brings me joy. Your observations and knowledge, combined with the information and directives in this letter and our conversations, will guide you to recognize the point at which a good death is better than a “heroic” medically-produced life.

Dementia, medications, or my physical condition may make it hard for me to recognize when that point has arrived. I am counting on each of you to be attentive to the quality of my life, know what I value, and be courageous in making the decisions necessary to end my life with dignity.

I intend to have a disciplined routine to give my life structure up to the end. Even as I become frail, I plan to feel joy and gratitude and continue doing everything I love, like nurturing my grandchildren, volunteering, writing, reading, giving talks, seeing friends, drawing, juggling, and playing the piano.

As my world contracts and shrinks, I intend to be at peace with that reality. I will look at society and accept that I am departing from it and that it will carry on after my death with barely a flicker.

How to Treat Me at the End of My Life

Before I begin actively dying, I'd like lots of visitors and to be surrounded by Gail, my daughters, sons-in-law, grandchildren, and great-grandchildren. I want my loved ones to combine grieving with celebratory food, drink, music, stories, roasting, and toasting.

As I approach the end, I would love to hear you recall our happy times together and your fun and joyful memories. It would bring me enormous pleasure to talk to each of you, including my beloved and precious grandchildren, about the good times we have shared. If conversation is no longer possible for me, your presence, your words, and your love will bring me comfort.

I'd love to have photos of my loved ones (all of you!) in my room near my bed. Also, I would like to have my hand held and to be talked to when possible, even if I don't seem to respond to the touch and voice of others.

At the end of my life, I would like to be kept fresh and clean, and I would like my lips and mouth to be kept moist to stop dryness.

I'd love to die at home with hospice care, but I realize that at some point, this may impose too big a burden on members of my family. If that is the case, then it's OK for me to spend my last days in Casey House, a beautiful inpatient facility with Montgomery Hospice www.montgomeryhospice.org.

I want to be conscious and lucid enough to say goodbye as I die. But, on the other hand, I also welcome pain control and realize that painkillers may make me drowsy and *non-compos mentis*. So, I am counting on you to help me juggle these two conflicting goals.

Please make sure that my doctors and nurses know about the kind of person I was before getting sick and senile. For example, show them a photo of me doing handstands in my 70s! And please protect me from well-meaning religious folk who want to convert me before I die.

I want my death to release love. I want you to celebrate my life, not mourn my death. My death is not a tragedy—at my age, no matter when death arrives, no one will say I died young!

I Want No Heroics

I love so much about my life—being active, spending quality time with grandkids, writing, giving talks, and volunteering—that if none of that is possible, I want to go out peacefully without a lot of medical heroics.

I want my doctor to refer me to hospice as soon as I am eligible. And if I'm in a hospital, I'd like a referral to palliative care at the earliest opportunity, even if undergoing curative treatment.

If it becomes clear that my remaining time is short no matter what treatments I receive, I'd like to do less instead of more. I do *not* want a tube put down my throat or inserted in my windpipe to keep me breathing. I do *not* want a PEG tube inserted into my stomach to feed me. Instead, I want a calm, gentle death.

If I'm severely compromised and unlikely to regain my ability to recognize loved ones, I consider my life over and want you to carry out my wishes for a peaceful death. If I have dementia and no longer recognize my beloved grandchildren, please do not work to prolong my life.

If I cannot respond to you with love and a sound mind, I ask you to collaborate with nature to see that my life ends as quickly as possible.

Please do not wait for advanced dementia, permanent unconsciousness, or terminal illness. An incapacitating stroke, an inability to move and think, stupor, delirium, or serious mental impairment should trigger the implementation of my exit strategy.

I see no purpose in prolonging my dying if it is painful, miserable, and hopeless. If I have lost all cognitive ability, I request that I *not* be spoon-fed.

I do not want my life prolonged by artificial means (medicines, machines, CPR, tube feedings, devices or techniques not yet invented, etc.) if I'm bedridden or cannot recognize and communicate with my family.

Seek Opportunities to Welcome Death's Approach

My life is full of loving, thinking, feeling, writing, talking, giving, teaching, volunteering, and laughing. If I cannot do those things and will never be able to do them, my life is over, and it's time for comfort care only.

If my mental function is seriously compromised with little chance for full recovery, please seek opportunities to encourage death's approach. Suppose, for example, I have pneumonia or another infection. Let my body go. Do not fight an infection with antibiotics if what remains after the drugs work is not worth fighting for. Are my kidneys faltering? Let them. Is my heart failing or my blood pressure falling? Do nothing. Am I refusing water and food? Good! Let it be.

Please look for what one expert in end-of-life issues, Dr. Joanne Lynn, calls "creative collaboration with the forces of nature." In other words, please take advantage of natural illnesses as they arise. Welcome my health failings as benefactors that have arrived to hasten my death. They should not be regarded as diseases to be attacked and combated with medical marvels.

I welcome aggressive pain and symptom relief while a disease takes its natural course, but artificially sustaining my life (that is, keeping me alive) while my quality of life drastically deteriorates would torment me unnecessarily.

If I Have Dementia

Advanced dementia is worse than death. I do not want to experience the end stages of dementia. I do not want to become seriously dysfunctional and very different from who I am today. Nor am I willing to experience substantially reduced mental function and an inability to talk and write.

Anything worse than mild cognitive decline is unacceptable to me and should trigger my exit strategy. I don't want the last years of my life to contradict all that went before, so I have added a dementia coda to my advance directive to underscore what I request in this letter.

If I have dementia, I am deeply concerned about the practical and emotional burdens this would put on those who love me and want to take care of me. Therefore, please remove all barriers to a natural, peaceful, and timely death. I want comfort care only. Please qualify me for hospice if you can.

Please make no attempt at resuscitation using CPR or any other method. Please ask my doctor to sign a do-not-resuscitate order.

Please do not authorize any treatment or procedure that might prolong or delay a natural death or prolong or increase my suffering. Do *not* intubate me. Do *not* give me intravenous fluids. Do *not* transport me to a hospital. Do *not* treat my infections with antibiotics, but give me painkillers instead. Please ask my medical team to deactivate all medical devices, such as defibrillators and pacemakers, that might delay my death.

Please do not coerce or even coax me to eat. If I'm eating, let me eat whatever I want. Do *not* allow a feeding tube for me. If one is inserted, please have it removed immediately. Please forbid dialysis. I want comfort care only, and I want to avoid all treatments that might be painful,

agitating, or prolong my dying. Please give me opioids to relieve any pain. If I need to be institutionalized, please send me to an inpatient hospice like Casey House.

My Right to Die

I believe that if I have an irreversible illness or intractable pain, I have the right to hasten the end of my life in any way I choose—a right to death with dignity. I want a good death if I can no longer enjoy a good life.

I support medical aid-in-dying (MAID) and want access to MAID medications (if legal) so I have the option of taking a lethal dose of medicine. I do not want my life prolonged artificially after it has ceased to be the life I want.

Pain Relief and Palliative Sedation

If I'm in pain, breathless, or agitated, I want those symptoms relieved quickly and vigorously with morphine, even if the treatment unintentionally advances the time of my death or even causes my death. It is more important to enhance my quality of life if I'm seriously ill, even if the treatment shortens my life.

With severe pain, intensely labored breathing (dyspnea), or agitation, I welcome palliative (terminal) sedation.

Voluntarily Stopping Eating and Drinking (VSED)

I will use VSED (voluntarily stopping eating and drinking) to die if necessary. When there is no hope for recovery, my life is near an end, and I am no longer enjoying being alive, and assuming MAID is unavailable, I will intentionally hasten my death using VSED. I will initiate VSED before I stop recognizing loved ones and cannot communicate. I believe that VSED is justified when the burdens of my life outweigh the benefits.

VSED causes death by dehydration within 8 to 14 days. Doctors say it is peaceful and causes little suffering *when adequately supported by good oral care and pain-relieving analgesics*. Its slowness also provides time for reflection, family interactions, and mourning.

I would rather end my life using VSED or MAID than suffer the despair of a lengthy stay trapped in an ICU on mechanical life support.

Because of the legality and availability of VSED, I don't think I will need to use the Swiss nonprofit Dignitas to end my life unless the hospice I'm using refuses to support me using VSED (or MAID if it becomes legal). However, I'm prepared to use Dignitas (or another similar Swiss nonprofit organization) if my other options for a peaceful exit are blocked.

I Plan to Obtain a DNR (Do-Not-Resuscitate) Order

When the time is right, I plan to obtain a DNR (do-not-resuscitate) order (i.e., no CPR) and a MOLST (Medical Orders for Life-Sustaining Treatment) from my doctor. DNR is also called DNAR (do-not-attempt-resuscitation) or AND (allow-natural-death).

MOLST will support my advance directive. An advance directive is ostensibly a legal document, while a MOLST is a medical order. A MOLST provides a tool for patients near the end of life to control their medical treatment better than advance directives alone, though both are important.

Please remember what I wrote earlier: if a hospitalist (a hospital doctor) chooses to ignore my advance directive and gives me painful treatments even though I have explicitly said not to, please sue them for medical malpractice and “wrongful prolongation of life.”

Such a lawsuit would help future dying people be treated with more compassion and teach hospital administrations that there are severe consequences for failing to adhere to an advance directive.

A Brief Ceremony After I Die (if it helps you)

I am indebted to author and science writer Katy Butler for the following idea. In many cultures, washing and anointing the body with oil after death is traditional. Katy Butler describes how nurses are now bringing a beautiful version of this ancient ceremony into hospital rooms.

This “bathing and honoring” practice may help loved ones say goodbye. A death doula could help facilitate it. Only do this ritual or ceremony if it is helpful to you. I’ll be dead, so at this point, all the focus is on all of you and what brings you comfort, solace, and peace.

OK, here is the ceremony: After I have died, perhaps my death doula or some of you might wash and dress my body (rather than letting my body be taken immediately to a funeral home). Then, if you felt like it, you could anoint my body with lavender oil using the following nurses’ ceremony:

As my hair is anointed with fragrant oil, a family member recites, “We honor Chris’s hair that the wind has played with.” Next, a dab of oil is gently rubbed on my brow as another family member says, “We honor Chris’s brow, the birthplace of his thoughts.” “Chris” would be replaced by “Dad” or “Grandpa” as appropriate. Then, the ceremony would continue as follows, with each line said by someone in the room, and my name (Chris, Dad, Grandpa) would be inserted as appropriate in each succeeding sentence.

We honor your eyes that have looked on us with love and viewed the beauty of the earth.

We honor your nose, the gateway of breath.

We honor your ears that listened to our voices and concerns.

We honor your lips that have shared so much wisdom and knowledge.

We honor your shoulders that have borne burdens and strength.

We honor your heart that has deeply loved us.

We honor your arms that have embraced us and held us.

We honor your hands that have held our hands and done so many things in this life.

We honor your legs that carried you into new places and new challenges.

We honor your feet that forged your path through life.

We give thanks for the gifts you have given us in our lives.

We give thanks for the memories that we created together.

We have been honored to be a part of your life.

I will write separately about my legacy letter, obituary, memorial service, and how to dispose of my body.

Thanks for reading this letter and implementing it to the best of your ability.

Love,

Chris/Dad/Grandpa

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#2: A LETTER TO MY DOCTOR

Dear Dr. Watkins,

It is important to me to have excellent and compassionate care and stay as healthy and active as possible throughout my life. Thank you for all you have done and will continue to do to preserve my health. When I approach the end of my life, I want treatment to alleviate suffering. Most importantly, I want to ensure that the experience can be peaceful for my family and me as death becomes imminent.

If measures are available that may extend my life, I would like to know their chances of success and their impact on the quality of my life. If I choose not to take those measures, I ask for your continued support, even if that choice goes against medical advice.

If my condition becomes incurable and death is the only predictable outcome, I would prefer not to suffer but rather die in a humane and dignified manner. Therefore, I would like your assurance that:

- You will tell me candidly and honestly when further treatments are futile.
- If it becomes clear that my remaining time is short, regardless of treatment, I want you to do less instead of more.
- If I can speak for myself, my wishes will be honored. If not, the requests from my wife Gail, and my advance directive (which you have) will be honored.
- You will make a referral to Montgomery Hospice as soon as I am eligible.
- You will support me with all options for a gentle death. These include VSED, palliative sedation, and, if medical aid in dying is authorized in Maryland, providing a prescription for medications I can self-administer to help my death be peaceful and dignified.

I hope for your assurance that you will support my personal end-of-life care choices as listed above.

I am attaching a letter to my family that explains how I want to be treated at the end of my life.

I hope you will accept this statement as a fully considered decision expressing my deeply held views. If you feel unable to honor my requests, please let me know now so I can make choices about my care based on that knowledge. Thank you.

Very best,

Chris Palmer

**#3: A LETTER TO MY FAMILY ABOUT ENDING MY LIFE
(IN CASE I EVER NEED IT)**

Drafted on December 7, 2022 (but the date on the final letter, if ever used, would be much later)

To my precious family and friends,

I have decided to end my life because of the continued pain and unbearable suffering from heart disease.

I have lived a full, complete, meaningful, and useful life, but I have had enough and no longer wish to continue.

I am a wreck and only a relic of the energetic, productive, and creative person I used to be.

I have taken advantage of all the available medical care and interventions. I have decided that further medical treatments are useless and will only hurt me and worsen my life.

This decision is mine alone. I am in a rational and calm state of mind and feel completely at ease with this decision. I am not depressed or mentally unstable.

No one has helped me with this decision to end my life, and no one, including the beneficiaries of my estate, has put pressure on me to do so.

I support the Final Exit Network (FEN) and believe in its mission. I have chosen to die now.

If I am discovered before I stop breathing, I forbid anyone, including doctors and paramedics, to attempt to resuscitate me. If I am revived against my wishes, I shall take legal action against anyone who helped in that action.

Please add the following language to my obituary:

“Chris took his own life in a rational self-deliverance toward the end of a terminal disease relating to his heart. He did this not out of cowardice or escapism but because it made no sense to continue living subhumanly with an unacceptable quality of life when nothing good or loving or kind could be accomplished. He died with a heart full of love, gratitude, and appreciation for all those he loved and who had supported him in his life.”

Thank you for your understanding.

Love, Chris/Dad/Grandpa

XXXOOO