

I'm Frail

— a supplement to "I'm Old" —

<http://thecsr.org/resource-directory/im-old-an-essay-on-aging-by-milton-crum/#sthash.e87C5Jyc.dpuf>.

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Three years ago I was writing "I'm Old." I was still driving, going shopping, walking half a mile with our dog across uneven terrain, climbing flights of stairs, and feeling pretty confident about my condition at 87. I still believed that my ailments and to some extent my wife Käthe's could be fixed by medical interventions.

In "I'm Old," I wrote, "I will probably not only *accept* death, but *welcome* it, if I no longer have significant . . . unfinished business that I am able to do." I also wrote, "as we approach death, many of us prepare by narrowing and simplifying our lives."

Moving into an assisted living facility fifteen months ago with Käthe was a radical narrowing and simplifying of our lives. I can still do a little writing, but Käthe is my primary joy and reason to get up in the morning.

Now after three more years of "age-related decline," I'm frail and I've almost had enough. So I am calling this paper "I'm Frail."

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Frailty

In *Rethinking Aging: Growing Old and Living Well in an Overtreated Society*, Nortin M. Hadler, M.D. sets out three markers of frailty: (1) loss of any notion of invincibility, (2) loss of possibility for a subsequent life stage, and (3) loss of ability to do things essential to one's care.¹ The first two markers apply totally. (1) Rather than feeling invincible, I feel increasingly weak mentally and physically. (2) I know that frailty is my last life stage. I was given a good and long life time, but I've spent almost all of it. (3) the third marker applies increasingly. I no longer drive, shopping is only by the internet, my walking is measured in feet on even surfaces, and I do no meal preparation. Even with eleven hours in bed at night trying to get as much good sleep as possible at my age, I feel tired all day. I can still take care of my personal hygiene, but that could also end if I don't die soon enough. My brain still functions, but my ability to read, comprehend, and write has slowed. I use no prescription medications except drops in my eyes to relieve ocular hypertension. My frailty seems to primarily a product of old age.

For most people (as documented by Muriel R. Gillick, M.D.) including Käthe, "frailty" denotes an array of chronic physical and mental problems which means that frailty is not treatable as a specific disease. These problems are often coupled with increased dependency in the basic activities of daily living (ADLs) required for personal care.² In Käthe's case, we are dealing with diabetes, sleep apnea, chronic heart failure, seizures, constipation, dementia resulting from brain atrophy caused by 18 years of small bleeding strokes and one clot stroke, and confinement to a wheel chair except for walks up to the 100 feet between our rooms with an aide, using a walker.

Thus, frailty usually comprises a group of distinct but interconnected "complex issues" and "comorbid diseases."³ These factors lead to progressive weakness, stress, and exhaustion.⁴ There are treatments for some of the causes of frailty, but "the ultimate course is a downward one."⁵

1. Nortin M. Hadler, *Rethinking Aging: Growing Old and Living Well in an Overtreated Society* (University of North Carolina, 2011), 159-160.

2. Muriel R. Gillick, M.D., *Lifelines: Living Longer, Growing Frail, Taking Heart* (Norton, 2001), x, xv-xvi, 5-6.

3. "diseases in addition to the primary disease"

4. Patricia M. Burbank, ed., *Vulnerable Older Adults: Health Care Needs and Interventions* (Springer, 2006), 25-26.

5. Victor G. Cicirelli, *Older Adults' Views on Death* (Springer, 2002), p. 4.

I have long said and hoped that I would die healthy, but I missed membership in that small minority. Käthe and I were assigned to the overwhelming majority that must endure a "phase of frailty" that might include dementia before we die.⁶

By reading and experience, I know about frailty. This is my definition. Frailty is a condition, sometimes lasting years, that most old people endure before death during which various ailments conspire to make death more attractive than life. For me, frailty has almost accomplished its goal, except for Käthe.

Käthe

The care provided and the life together made possible by our assisted living facility for Käthe and me during our 15 months in residence have been as good as possible given our conditions. Nevertheless, virtually all the people, activities, and possessions that enriched our lives in former days have been taken away except having each other and our days together.

So far, I have been permitted by the facility and I am still able to be Käthe's primary care taker from arising to going to bed (each with a kiss) for transfers, exercising, and entertainment making much use of the internet. Käthe tells me that she is happy in this situation and she seems to be. She once told me that she did not like receiving care from the staff because it makes her feel too dependent, but she added, "I don't mind being dependent on you because I love you and you love me."

We have talked about longevity having lost the attraction it once had and about our dread of being left alone and how life would not be worth living. Käthe's ability to articulate her thoughts is limited, but she expresses her feelings. Asked about life without Milton, she says, "I wouldn't want to live, if I could help it." I feel the same way about life without Käthe.

Without the present arrangement with Käthe, I would be hard pressed to find sufficient reasons to get up in the morning. Even with Käthe, I have begun to feel that I've almost had enough living without the people, possessions, and activities that once comprised my life.⁷ No matter what

6. Muriel R. Gillick M.D., *Choosing Medical Care in Old Age: What Kind, How Much, When to Stop* (Harvard, 1998), 189.

7. An exercise used to simulate old age is to divide fifteen slips of paper into three groups on which to write (1) your most important people, (2) your most enjoyable activities, and (3) your most treasured possessions. One-by-one the slips are taken away.

anyone does, from now on it's downhill toward death. We are both in what is our final stage and what it is to be hoped the shortest.

A Day of Frailty

Up at 6:30am, exercise in an attempt to maintain some strength. 7:15am, walk 100' to Käthe's room for a good morning kiss after which she gets a snooze. I have coffee and newspaper before helping Käthe get up and dressed: helping with transfers from bed to walker to toilet, a little washing up and getting dressed, transfer from toilet to walker, walk across room to wheelchair. With help of an aide, Käthe usually gets a pre-breakfast 100' walk. Then come her diabetic procedures and breakfast. Käthe's upper-body exercises come next in my room accompanied by music from the internet. After that, it's back to her room for brushing teeth and a 90 minute nap. 11:30am repeats much of Käthe's getting up plus a few leg exercises and the diabetic procedures before lunch.

After lunch, in my room until another walk for Käthe before her 2:00pm nap. For entertainment, we use internet radio or YouTube, sing children's or love songs, work together on a six piece jigsaw puzzle, or talk. After the nap, another walk and time in my room for tea, crackers, and music before the diabetic procedures and supper. After supper, it's a shower for Käthe on two evenings. The other evenings we spend time in my room enjoying something on the internet until getting ready for bed. Käthe's bedtime is about 6:30pm; mine is as soon after as I can make it.

During Käthe's nap times, I do my personal hygiene, place orders, pay bills, check finances, and write things like this. The days go by quickly; I don't have time on my hands.

This is a life radically narrowed and simplified compared to what it was even two years ago. The surprise is that we don't feel stir-crazy. It's because frailty down-sizes everything about us: our energy, our brains, our interests. We remember and are saddened by the loss of earlier activities, possessions, and contacts, but we accept their demise. We enjoy family visits and knowing they are there provides an invaluable assurance, but we don't yearn to see them every day. Going to a fine restaurant has lost its appeal. Käthe's brain seems to have lost its ability for culinary discrimination and I no longer hunger for fine food.

Life as a frail person is vastly different from life as merely old: a

transformation that can happen quickly or gradually.⁸

Death

We have long anticipated death in a rational way by making end-of-life arrangements, executing documents, and writing guides to help our survivors do the many things that survivors need to do. But now that the conspiracy of old age and ailments has wrought us frail, death has taken on a new reality; it's at the door. Neither our assisted living facility nor our doctors can restore us to a pre-frailty condition. At best, they can make the time between now and death as pleasant as possible. I hope that the assisted living facility will not think it their duty to take away whatever pleasures we still enjoy in an attempt to prolong our lives. And I hope that our families or our doctors will not feel obligated to stretch out our lives.

Most of the age 85+ interviewees in *Life Beyond 85 Years* did not fear death, but nearly all dreaded a long process of dying. One woman said, "living this long is pure hell. The hardest thing I face is having to go on living." Käthe and I both hope that we will not be like this person and have people making efforts to extend our misery, perhaps assuming (without ascertaining what we want) that they are doing us a favor.⁹

As of this writing, life cannot be described as "pure hell," but we would not have chosen our present situation except by necessity. And we see other residents in conditions that, to us, fit the "pure hell" description.

Facing our Death

In his *How We Die*, Dr. Nuland lays out two options as we face our death. One is to battle death using all the weapons of "high-tech biomedicine." The other option is to consciously acquiescence to death's power.¹⁰ We are choosing the second option. In this choice, we are with the majority in *Older Adults' Views on Death*, a study based on interviews with people in the 70-97 age range, with a mean age of 80.7. About half the people chose doing nothing except live day by day until death comes naturally without medical or other intervention designed to prolong life. This choice was coupled with a

8. Muriel R. Gillick, M. D., *Lifelines: Living Longer, Growing Frail, Taking Heart* (Norton, 2001), 5-6.

9. Colleen Johnson and Barbara M. Barer, *Life Beyond 85 Years* (2003), 202-206, 208.

10. Sherwin B. Nuland, *How We Die* (1995), 10.

desire to receive palliative care if needed.¹¹ We both concur with this choice.

Even when it's possible to postpone death, doing so often afflicts the frail person with "prolonged sickness, dependence, pain, and suffering."¹² Postponing death is also costly in dollars. One out of every four Medicare dollars is spent on the frail in their last year of life in attempts to postpone death.¹³ Dr. Hadler warns against the tendency to medicalize and overtreat the frail.¹⁴

There are two Greek words for "life." *Bios* denotes biological life; *z  e* denotes real and genuine life.¹⁵ We choose not to extend *bios* after frailty precludes *z  e*. It would be nice to have other choices such as again living robustly in Alpine Lake in West Virginia where we enjoyed twenty glorious retirement years. As goes the song, "those were the days, my friend, we thought they'd never end," but they did.¹⁶ As I was writing these words, K  the joined me in singing them. She then mused, "that's the way it is with people who had a good life: they wonder where it went."



Old Age Evokes Memories

*Youth anticipates a future,
old age remembers a past.*

"Nothing is ever really lost
to us as long as we remember it."*
Is this assertion true for you?
For us, the happier the memory,
the sadder the remembering.
Illness, infirmity, and death have stolen
the essentials of the happy times:
Stolen people we loved,
activities we enjoyed,
places we can never see again.
We can remember them,
but we have lost them.

**The Golden Road*, Lucy Maud Montgomery

11. Victor G. Cicirelli, *Older Adults' Views on Death* (Springer, 2002), 6-7, 9, 12, 32.

12. Patricia M. Burbank, ed., *Vulnerable Older Adults: Health Care Needs and Interventions* (Springer, 2006), 9.

13. Penelope Wang, "Cutting the high cost of end-of-life care" (CNNMoney, 2012).

14. Nortin M. Hadler, *Rethinking Aging: Growing Old and Living Well in an Overtreated Society* (University of North Carolina, 2011) 1, 3.

15. *Strong's Concordance* <http://biblehub.com/greek/979.htm> and *Thayer's Greek Lexicon*, <http://biblehub.com/thayers/2222.htm>.

16. From the song used in movies, TV, and often recorded in many languages. See [http://en.wikipedia.org/wiki/Those_Were_the_Days_\(song\)](http://en.wikipedia.org/wiki/Those_Were_the_Days_(song)). "Those were the days my friend. We thought they'd never end. We'd sing and dance forever and a day. We'd live the life we choose. We'd fight and never lose, for we were young and sure to have our way."

Detente with Death

In his *Rethinking Aging: Growing Old and Living Well in an Overtreated Society*, Nortin Hadler, M.D. describes the unreality of trying to cure ailments in the 9th decade. (Käthe is not there chronologically, but she is there functionally.) In Dr. Hadler's judgment,

it makes no sense to cure the diseases one will die *with* in the ninth decade and little sense to cure the disease that one will die *from* in the ninth decade if another is to take its place in short order.¹⁷

For all ages, there is evidence that attempts to cure can do more harm than good and the procedures can inflict misery.¹⁸ A *Newsweek* article "One Word Can Save Your Life: No!" found that "more health care often means worse health."¹⁹

What all of us face is described by Dr. Sherwin Nuland in his *The Art of Aging*: a lifelong process in which "a healthy individual . . . gradually deteriorates into one that is frail . . . vulnerable to disease and ultimate death."²⁰ In his *How We Die*, Dr. Nuland argues that many people die of "old age" even though doctors are required to name some disease as the cause.²¹

Taking it as it Comes

A 100-year-old friend often advised, "you've got to take it as it comes." This is what he did and it's what we are increasingly doing. Battling death requires exceptional effort and perseverance and whatever life extension is won may be less attractive than death.

By choice or necessity, we have already reduced potential medical care and ceased some of our own efforts to postpone death. No longer do we eat only whole grain and the leanest meat; no longer do we drink only skim milk. I have skipped the five-year blood work and checking moles. I sometimes feel

17. Nortin M. Hadler, *Rethinking Aging: Growing Old and Living Well in an Overtreated Society* (University of North Carolina, 2011), 175-176.

18. Penelope Wang, "Cutting the high cost of end-of-life care" (CNNMoney, 2012).

19. "One Word Can Save Your Life: No!" *Newsweek*, August 14, 2011.

<http://www.thedailybeast.com/newsweek/2011/08/14/some-medical-tests-procedures-do-more-harm-than-good.html>.

20. Sherwin B. Nuland, *The Art of Aging: A Doctor's Prescription for Well-Being* (2008), 27-28, 59.

21. Sherwin B. Nuland, *How We Die* (1995), 43-44, 72.

like my whole system is about to conk out, a feeling for which I would have seen a doctor in the past. Now, I take it as a possible quick way to die without a fearful lengthy process. With the concurrence of all three daughters we have cancelled appointments with Käthe's cardiologist. Käthe was first sent to a cardiologist several years ago by our primary care physician to get her blood pressure under control and that has been done. We also canceled a check of Käthe's Pacemaker because what the Pacemaker technician had told me about the low risk of malfunction seemed less than the risk of transporting Käthe in midwinter.

When Käthe had her first seizure, she was sent by ambulance to the ER where she underwent the usual round of tests and an attempt to have her see a neurologist which we declined. There have been three more seizures in which Käthe was simply placed in her bed for rest and recovery. It is not clear whether permanent damage was done, but it does not seem that another visit to the ER would have helped. If, in spite of our wishes not to, we get as far as the ER or ICU, we have made legal decisions by executing DNRs, POLSTs, Living Wills, and Medical Powers of Attorney for each of us.

I am thinking that what we want for our time left is called "palliative care."

The basic philosophy of palliative care is to achieve the best quality of life for patients even when their illness cannot be cured.²²

Palliative care is done by "relieving or soothing the symptoms of a disease or disorder without effecting a cure."²³

Another factor is Käthe's multiple illnesses (multimorbidity) situation: a condition shared by about 75% of people over 65, probably more at our ages. I might find multimorbidity in me too if I had a physical exam. My blood pressure runs about 30 points higher than it used to, but I have arrived at a point where I am more interested in a good way to die than I am about treatments to extend life.

Johns Hopkins Medicine points out that treating each illness as if it stood alone can be detrimental.²⁴ For anyone thinking about the multimorbidity

22. Stephanie C. Paulus, "Palliative Care: An Ethical Obligation" (Markkula Center for Applied Ethics, Santa Clara University, 2008).
<http://www.scu.edu/ethics/practicing/focusareas/medical/palliative.html>.

23. <http://www.thefreedictionary.com/palliative>

24.

http://www.hopkinsmedicine.org/geriatric_medicine_gerontology/aging_research/health_services_research/multimorbidity.html

factor, the "Guiding Principles for the Care of Older Adults with Multimorbidity Pocket Card" from The American Geriatrics Society might be useful.²⁵

Religion and Faith

I have long since resonated with Karl Barth's dictum that "religion is the enemy of faith."²⁶ Except for attending Sunday worship with Käthe at the National Cathedral via their website, religious practices are not playing a role in my life.

However, several faith affirmations and images are operative for me. Most of them are contained in three items written by me, available on the internet.

- "Self-esteem/OKness: a personal story" online at <http://www.ahpcc.org.uk/pdf/selfesteem.pdf>
- "Enduring Significance in My Faith" online at <http://www.ahpcc.org.uk/pdf/enduring.pdf> or search <http://books.google.com> for "Enduring Significance in My Faith" to bring up a link to it as found in Robert W. Chism, *Longevity Response-Ability*.
- *Evil, Anger, and God*. Go to <http://books.google.com> and search for Milton Crum *Evil, Anger, and God*.

Walking through the "valley of the shadow of death," it is the evil of an extended frailty that I fear more than death. (Psalm 23:4)

What's Next?

The odds are for a "progressive terminal decline" with constant fatigue, more sleep, increased detachment from people, things, and activities until we die.²⁷

Both of us have executed POLSTs, Living Wills, and Medical Powers of Attorney and they are on file with the assisted living facility and our primary care physician who works for our local hospital. Our concern about what's

25. "Guiding Principles for the Care of Older Adults with Multimorbidity Pocket Card" from The American Geriatrics Society.
<http://www.americangeriatrics.org/files/documents/MultimorbidityPocketCardPrintable.pdf>

26. Quoted in *Boston Collaborative Encyclopedia of Western Theology*,
<http://people.bu.edu/wwildman/bce/barth.htm>.

27. Colleen Johnson and Barbara M. Barer, *Life Beyond 85 Years* (2003), 207.

next relates to the possible time between when we become too frail to continue our present life style and before we are clearly terminally ill and the end-of-life directives become applicable.

With our assisted living facility, it's so far, so good. It is what's next that I am pondering. The way I imagine what's next is based partly on written descriptions of the likely future for us between now and our deaths, such as those I have cited. My imagining is also based on the care of old people (sometimes including Käthe and me) that I have observed over the years in three different states in churches and commercial care facilities. Some of these memories include the following:

Disturbing Memories

- There was a very old invalid woman in our church who often said that she was tired of living and wanted to die. None of us took her seriously because none of us understood old age well enough to comprehend that she might have been totally serious. My seminary training included nothing about ministering to what Dr. Gillick calls the "frail elderly."²⁸
- I recall Sally whose greatest pleasure seemed to be hot chocolate, but it was ordered that she get no hot chocolate unless she ate more. On one visit, I heard an aide telling Sally that she must eat before she could leave the table. When Sally protested, the aide argued that the food was good for her and that it would make her healthy. She asked the aide, "why are you so mean to me?"

Did anyone ever ask Sally whether she would have chosen to live longer eating and drinking "right" or die sooner eating and drinking whatever she wanted. Did anyone listen to her wishes about her life and death?

I hope that as a 90-year-old I will not suffer being patronized as a child. I hope the same for Käthe. There was a time in the past when she was so treated by a staff's comments about what she was eating. Käthe said, "it made me feel like a child. It made me feel dumb."

I would hope that Käthe and I will not be deprived of any pleasures we have

28. Muriel R. Gillick M.D., *Choosing Medical Care in Old Age: What Kind, How Much, When to Stop* (Harvard, 1998).

left even if the depriver's intention is to extend our lives.²⁹ What's a name for making somebody live against her/his wishes?

- In another place, there was an 85+ man who ate every bite of the high calorie servings given him and I saw him develop a Santa Claus stomach. So it seemed permissible to shorten one's life by overeating.
- I am thinking about frail people whom I have seen put on oxygen or nebulizers. Was it for palliation or trying to postpone the death of people whose lives were limited to sleeping, being cleaned up, and eating?

Reassuring Memories

Regarding our desire for palliative care without heroic measures, I am thinking of people about whose last days I had some knowledge.

- One person was very frail on arrival at a facility and was confined to her room where she died after some weeks. There were no heroic medical interventions.
- Another person had a fall and was placed in a nursing care facility where he died sometime later. Again, I heard of no heroic attempts to prolong his life.
- A 90+ friend was sent to the hospital with pneumonia. He was offered a radical intervention that might extend his life. He declined. It was as if he had read Dr. Hadler's warning cited above on page six.
- When I first met this person, he was walking well with a walker and eating heartily. He went downhill rapidly until he died from heart failure. He was given morphine at the end, but I think there were no heroic medical interventions.

The most we can hope for as our frailty compounds is that our care will contribute to the primary goal for Käthe and me, namely, maximizing

29. In the 1990 case of Nancy Beth Cruzan before United States Supreme Court, "the majority assumed . . . that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition." Annette E. Clark, "The Right to Die: The Broken Road from Quinlan to Schiavo" in the *Loyola University Chicago Law Journal*, Vol 37 (2006), 394. Online at <http://www.luc.edu/media/lucedu/law/students/publications/lj/pdfs/clark.pdf>

pleasure and minimizing suffering with no illusion of curing either of us and with recognition that our decrepitude will inevitably increase.

Discussion and Decision

Recognizing that our present life that we find worth living will end and will likely end while we are still alive came as a call to discussion and decision.

Käthe, two daughters who live nearby, and I began conversations about what kind of care we hoped for from our assisted living facility and our physician. Readings such as those cited above helped us analyze our situation and project likely futures.

We agreed on the following letter to the assisted living facility owners and staff which includes registered nurses and our physician. We thought such a letter important because doctors and nurses are trained for and in their practice focus on fighting disease and extending life. It is reportedly difficult for some of them to shift focus from extending life to palliative care.³⁰

Letter sent to Assisted Living Facility and Primary Care Physician

We're writing this letter in response to Milton and Käthe's wishes that their desires regarding life-extending care be clearly communicated and understood by all of us. We've had recent conversations with Käthe and Milton regarding their strong wishes regarding refusal of life-extending care.

As you know, both Käthe and Milton have executed POLSTs, Living Wills, and Medical Powers of Attorney. They are on file with *Facility Name* and *Primary Care Physician*. Käthe and Milton's present concerns have to do with the possibility that one-of them may have illness, complications, etc., before they are clearly terminal and their end-of-life directives become applicable.

They describe their present conditions as allowing for a 'worth-living quality of life,' but are clear that much increased frailty, disability, or illness would result in a 'not-worth living quality of life.' And they have independently expressed their desire that the focus of their care be palliative rather than life-extending.

We are writing this to you because we want you to know their desires,

30. Virginia Morris, *Talking About Death* (Algonquin Books, 2004), 245-247.

and Heather, Cindy and Suzanne's support of Käthe and Milton's desires; as well as to assist in freeing you from legal or moral obligations to do everything possible to make Käthe and Milton live longer. Käthe and Milton both value the quality of life more than the length of life, and without sufficient quality they do not want to live longer.

Some specific wishes and choices from Käthe and Milton follow:

- Honor our right to refuse treatment.
- Do whatever is needed to alleviate pain even if it hastens death.
- Do not administer oxygen or a nebulizer unless they can relieve suffering.
- Allow us to determine what or how much we eat or drink.
- Do not feed us things like Ensure or Mighty Shakes as a way of extending life.
- Do not call ambulance and send to ER or ICU.

Heather, Suzanne and Cindy are supportive of Käthe and Milton's wishes regarding the above specifics. If you would like to meet with us to discuss further, we are readily available to get together. Thank you for the care you are giving.

Appreciatively, signed by Käthe and Milton Crum and three daughters

Epilogue

I have read this paper to Käthe. She found it "realistic" but "sad." Asked if things could be different, she said, "not without a miracle, but that's unlikely." I agree. At one point, Käthe asked that we not read anymore because it was "too emotional." We took a break.

This will probably be my last writing about old age. I hope that families of old people, as well as the doctors, nurses, and aides who care for them, will listen to the old people themselves about their choice between life-extending care and palliative care. Listening sometimes requires patience and alertness for non-verbal communication. It also requires laying aside the assumption that everyone wants to be kept alive regardless of quality of life. However, the book *Older Adults' Views on Death* illustrates that their views can be elicited.

Milton Crum