Living Every Minute

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On Halloween 2013, I went to the emergency room with chest pain and shortness of breath. Thus began our odyssey with acute myelogenous leukemia (AML). I say “our” because this journey has emphasized how I live within a network of relationships that includes self, family, community, and colleagues. If I have learned nothing else, it is my interdependence with others that provides love, joy, and peace in my life. Much to my surprise, I chose to undergo eight months of aggressive chemotherapy and at the time was in “cytologic remission.” As of January 2015, this is no longer true as my leukemia has relapsed. I have a 24.5% chance to be alive in five years or conversely, a 75.5% chance of dying anytime before. Of course the reality is I will either be 100% alive or 100% dead and no one knows what will happen in advance. Which is true not only for me, but for everyone.

Four months into our journey, Annalu, my wife and caregiver, also was diagnosed with AML. She chose to undergo the same aggressive chemotherapy. So for four months we were both patients and caregivers simultaneously. It is impossible for us to adequately express our gratitude to the family and friends who swooped in to support us during that “twilight zone” time. Annalu was initially in remission but has since relapsed and is receiving palliative treatments. The reality is that my beloved wife will die within the next year.

I am now her main caregiver and expect to survive her, although one can’t be sure. We have learned to live with uncertainty. As her caregiver, we both experience the vicissitudes of her illness and I witness my own future. We awaken each day expecting the best, accommodating to whatever happens, and to the best of our ability, avoiding the worst. No surprise to us, physical suffering is the foundation of the worst but medicalization of our lives is a close second.

This article is an effort to share what I have learned over the past year both personally and professionally. In this effort, I use poetry to express complicated and often ineffable lessons I have experienced, often at the deepest levels of my being. I encourage you to read each poem to yourself and reflect on those lines that speak directly to your heart. Explore what is within you that connects strongly to these poems and to my comments. These are the lessons I wish to leave you with.

Two Worlds

My heart is full of good intentions. I want to help using all I know. I know a lot you don’t know about diagnosis, treatment, risks, benefits, statistics. How can I assure you know enough so you can make the right choices? I protect my heart so I am safe from making choices, from sharing your life.

My heart is full of life. I know a lot you don’t know about love, hope, grief, fear, illness, mortality. How can I help you know enough about who I am so you can help me make the right choices? So we can share our knowledge and our lives?

~ Stu Farber

The fundamental lesson I have learned as a professional patient is that clinicians and patients/families inhabit two entirely different worlds. Unfortunately,
the medical world is the one that holds dominion. The surging currents of medicine sweep everyone down a river rushing toward life-prolonging treatment as inevitably as the tides follow the moon. The fallacy that I am an autonomous individual who can and should make treatment decisions based on the medical facts provided by my clinicians continues to confront Annu and I at every medical crisis point. Discussions focus on treatments to prolong life and make invisible the very life we are living. This medical model protects clinicians from having to make tough decisions and having to engage with their patients and families on an intensely personal level.

As I sat in my hospital bed following my second round of intensive consolidation chemo and seven days of neutropenic fever, the infectious disease (ID) attending shared that I likely had a viral infection that my returning white count should take care of. However, there was a small chance I had PCP pneumonia, and if that was the case, then without treatment I would die. The best way to be certain I didn’t have the lethal PCP pneumonia was to have a bronchoscopy. He then asked me, “What do you want to do?” I smiled to myself as I considered his question. First, I was in no shape to decide much of anything given how muddled my mind was by both sickness and grief. But the answer arose from within my inner self. “I don’t want to do anything that would make me feel worse. I feel a bit better now than when I came into the hospital. I want to wait and see if I continue to improve. There is a very small chance I have PCP pneumonia and a very large chance I have a virus that will get better. If I’m wrong, I am at peace with the consequences, including death.” Much to my surprise the ID attending said, “That is the same choice I would make.” I was dumbfounded. Every word he shared led me to think he wanted to do a bronchoscopy. I am convinced that almost every patient who participated in the same discussion would opt for a bronchoscopy. How can this be? It is craziness. Yet it is repeatedly our experience. How to integrate these two worlds into one shared world is the critical challenge.

**The Guest House**

This being human is a guest house. Every morning a new arrival.

A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor.

Welcome and entertain them all! Even if they’re crowds of sorrow, who violently sweep your house empty of its furniture,

Still, treat each guest honorably. He may be clearing you out for some new delight.
The dark thought, the shame, the malice, meet them at the door laughing, and invite them in.

Be grateful for whoever comes, because each has been sent as a guide from beyond

~ Rumi

So what have I learned from my new friend Leukemia? Personally, I always knew that I was going to die. I just didn’t believe it. Now I get it to my core. I am mortal. Knowing I am mortal is a sacred knowledge that makes each moment an awesome gift filled with opportunity for love, joy, and peace. It has transformed how I live my life. If I know I am mortal, then what is important? Sharing love and joy within my relationships: with myself, my wife, my family, my grandchildren, my friends, my colleagues, and the community in this very moment we are living.

Professionally, I understand in a deeper way that death is not a medical event. It is a central life cycle event that we will all successfully complete, no matter how much medical care we get or don’t get, or how healthfully we live or don’t live our lives. Death is a process to be lived not a problem to be solved. Yet literally every clinician Annu and I have interacted with is more afraid of death than we are; they focus on solving the problems of our illness with little awareness of how we want to live our lives. It is a paradox. The clinician is focusing on “treating” the illness that threatens life, but the “life” of the person who is ill is invisible. It is critical for clinicians to embrace death as a normal part of life, so they can accompany and guide the patients and families they serve through the sacred process of living until death.

**The Way It Is**

There’s a thread you follow. It goes among things that change. But it doesn’t change. People wonder about what you are pursuing. You have to explain about the thread. But it is hard for others to see. While you hold it you can’t get lost. Tragedies happen; people get hurt or die; and you suffer and get old. Nothing you do can stop time’s unfolding. You don’t ever let go of the thread.

~ William Stafford
I spoke above of the paradox of clinicians treating serious illness and patients living their lives. Our experience has starkly taught me just how disconnected my clinicians are from having a curiosity about my thread. There is comfort residing in the abstractions of the biomedical model. My story becomes one of diagnosis (AML), prognosis (bad), and treatment plan (chemo protocol). All this information fits nicely on the Excel spreadsheet that defines my medical story. Why talk with me or even examine my body carefully when the CT scan or bone marrow biopsy provides better answers for my treatment? With rare exception, the clinicians who treated me have good hearts, care deeply, but possess little or no knowledge of my thread. My thread is the narrative I use to make sense of my life. It is longitudinal, non-linear, emotional, filled with contradictions, and integrates my life experiences into a coherent whole. It is within the values and meanings of my story that treatment decisions are made. What contributes to meaning and quality is not about living longer but living a life that is consistent with my thread. Without knowing my thread, it is impossible for a clinician to provide respectful care.

To the handful of clinicians who were patient-centered (i.e., understood my medical goals), I am eternally grateful. To the four clinicians who understood my thread, I cannot express the depth of my appreciation. This gap existed with every discipline and left me feeling that, while well meaning, most providers are mostly nuisances and at times major annoyances in my daily life. Palliative care is a work-around, not a solution. Radical system change is needed that includes a fundamentally new alliance among patients, families, and professionals.

Paradox

It is a paradox that we encounter so much internal noise when we first try to sit in silence.

It is a paradox that experiencing pain releases pain.

It is a paradox that keeping still can lead us so fully into life and being.

Our minds do not like paradoxes. We want things to be clear, so we can maintain our illusions of safety. Certainty breeds tremendous smugness. We each possess a deeper level of being, however, which loves paradox. It knows that summer is already growing like a seed in the depth of winter. It knows that the moment we are born, we begin to die. It knows that all of life shimmers, in shades of becoming—that shadow and light are always together, the visible mingled with invisible.

When we sit in stillness we are profoundly active. Keeping silent, we can hear the roar of existence. Through our willingness to be the one we are, we become one with everything.

~ Gunilla Norris

It is a false choice asking me to choose between life and death, certainty and uncertainty, hope and fear. The reality is that all these things are happening simultaneously. I have AML that will shorten my life (certainty) but how it will shorten my life is unknown (uncertainty). I know specific consequences of choosing certain medical treatments such as doctor appointments, side effects, length of treatment time (certainty) but I don’t know how the benefits or burdens of these treatments will manifest (uncertainty). My life remains full of hope, joy, and love while simultaneously filled with fear, sadness, and grief. Living in paradox is not a strength of my medical providers. They strive for the clarity and safety the biomedical model provides. Focusing on precision (i.e., process of limiting uncertainty) to provide the hoped-for hope of extending life leaves everyone unprepared for diminishment, resulting in immense suffering for all.

Annalu and I have found living in paradox allows us to expect the best (sometimes a stretch given my palliative care background), be prepared for how to live if the best doesn’t happen, and clearly define the worst so we can avoid it. Openly discussing the worst has not made it happen but rather the contrary: it has helped us avoid treatments that are inconsistent with our threads. It also has led to difficult discussions for our providers who were stretched to continually prepare for all outcomes (including the worst) throughout our illness. Overall, it has greatly relieved everyone’s distress in our uncertain situation.
Choices

Try to choose carefully, Arren, when the great choices must be made. When I was young, I had to choose between the life of being and the life of doing. And I leapt at the latter like a trout to a fly. But each deed you do, each act, binds you to itself and to its consequences, and makes you act again and yet again. Then very seldom do you come upon a space, a time like this, between act and act, when you may stop and simply be. Or wonder who, after all, you are.

-Ursula K. Le Guin

Ira Byock talks about human beings and human doings. One of the most cherished gifts of my illness is to be “between act and act ... simply be ... wonder who I am.” In reflection, I more deeply appreciate that as a physician, I was taught to act and defined my worth by my actions. I treasure times of simply “being present” with others in a new way. I also am aware how rare it is for clinicians to simply “be” with me and how “bound” they are to action.

The Unbroken

There is a brokenness
out of which comes the unbroken,
A shatteredness out of which blooms the unshatterable.
There is a sorrow beyond all grief which leads to joy
and a fragility out of whose depths emerges strength.

There is a hollow space too vast for words through which we pass with each loss, out of whose darkness we are sanctioned into being.

There is a cry deeper than all sound whose serrated edges cut the heart as we break open to the place inside which is unbreakable and whole, while learning to sing.

~ Rashani Rea

Loss and grief have been inseparable companions for Annalu and I during this past year. Our grief is the natural response to the many losses we have experienced. Grief is neither a problem to be solved nor a disease to be cured. It is a process to be experienced and supported that has added richness and meaning to my life I did not know possible. Once again, grief has been one of the many paradoxes that has leavened my life. As a patient, I have been amazed at the distance my providers keep from my grief, and when it is touched, how quickly they are “bound” to “fixing” it. Most of my clinicians are so busy protecting themselves that “being with me” is not possible. The lack of acknowledgment and support of my grief is a profound personal and professional lesson for me.

When All That’s Left Is Love

When I die
If you need to weep,
Cry for someone
Walking on the street beside you.
You can love me most by letting
Hands touch hands, and Souls touch souls.
You can love me most by
Sharing your simchas (goodness) and
Multiplying your Mitzvot (acts of kindness).
You can love me most by
Letting me live in your eyes
And not in your mind.
And when you say Kaddish (prayers) for me,
Remember what our Torah teaches,
Love doesn’t die People do.
So when all that’s left of me is love give me away.

~ Rabbi Allen S. Maller

One of the most meaningful lessons I have learned in the past year is the power of legacy. When I was first diagnosed, I was filled with an anxiety that was physically palpable. Reflecting on my feelings I realized the major cause of my anxiety was a fear of not being able to share with my family and community how much I loved them and what I valued in our relationships. It was devastating to imagine all our mutual loving and caring would be lost and forgotten. Over the next frenzied week, I wrote letters to my wife, sons, and grandchildren sharing my love, acknowledging their gifts and describing my hopes for them. I am an amateur guitar player/singer and recorded songs for them to play at my wake. At the end of that week, my
anxiety was greatly calmed. I have continued to create legacy in many ways and have found it to be rewarding. I am both sharing the love and wisdom I want those I care about most to remember as well as opening myself up to provide to them the gifts they want from me. This is something I should have been doing all my life and not as I sit on the brink of mortality.

Creating legacy has left me with a profound sense of completion. The wisdom and caring I have garnered in my life will continue to live in the hearts and spirits of those I love. While I may be physically absent, my legacy will be actively living in relationship to those I care about most. It is my form of mindful immortality. It is the reason I am sharing these words with you, my palliative care community.

Professionally it has deepened my understanding of how important legacy creation is for patients, families, and communities. This hard and rewarding work is difficult to engage. Yet it is deeply rewarding for those who do it and their families. Finding ways to engage patients and families in creating legacy is a sacred opportunity for clinicians. Professionals aren’t doing the work but are inviting patients and families into a safe environment where such deeply human connections can be explored and expressed.

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Editors’ Note: Dr. Farber died peacefully at home with hospice on February 27, 2015. Getting this article published was an important part of his legacy work and it contributed greatly to his meaning and purpose knowing that he may not live to see it in print. He will be missed by all.

References


Late Fragment

And did you get what you wanted from this life, even so?
I did.
And what did you want?
To call myself beloved, to feel myself beloved on the earth.

~ Raymond Carver

As I gaze into mortality, love sits in the center of my consciousness. Love is the inspiration that creates my courage to move forward as a caregiver to my wife, a patient receiving care, a father accepting support from my children, and a human simultaneously living and inevitably dying in the miracle of this world. As I sit with my medical caregivers, I see fear of failure at the center of their consciousness, with death being the ultimate defeat. These professionals actively, albeit unconsciously, convey that living longer is always preferable to dying, but they fail to appreciate that the most important act is to support living in harmony with a narrative thread. It is another of the many paradoxes that I live within. I leave my insights as a legacy for others to reflect upon and use as they see fit for the benefit of themselves and all those they touch.