

LITERARY CLUB PAPER
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TWELVE MONTHS: DIARY OF A YEAR TO LIVE

Writing about dying is never easy. Writing about your own dying is even harder.

Listening to a paper about dying is never easy. Listening to a paper about the dying of someone you know, or a friend, is even harder.

Some of us, in medicine, in law, in the clergy and in finance, say to ourselves we deal with the dying of others every day. Yet, for me, confronting my own death was different.

As I completed this diary, the idea of reading it as my paper to the Literary Club crossed my mind, but I was leery. I consulted with a few of you who know most about this subject. You supported the part of me that thought reading it would be useful. The other part of me remains cautious, wary of the risk of opening too private and vulnerable a space in me or in you.

So, trying to keep that in mind, I begin.

November 24, 2014

“Twelve months, maybe eighteen if we’re lucky.”

Young, earnest, informed,
His eyes lock with mine
His mind filled with the pain of loss,
I suspect the last patient
He treated with my condition,

After all, he was only answering the question I posed
The one I had so carefully crafted

“Doctor, what is the arc of my illness?”

I felt Joanne’s hand rest on my arm
While I disappeared from my mind.

December 7, 2014

Blindsided I stagger
At what I have known since a child,
That our days are numbered
Yet when the number of my days is announced
I react as if ‘this were never to be.’

I am ashamed at my blindness
My belief that death does not apply to me

I struggle to find metaphor, words that might make the alien territory of death more familiar. Being hit with a wild pitch doesn't get it, this is too disorienting.

New Lens

I falter in my Fiat 500,
As I try to view the road ahead

There is conversation
About the future

But my rear-view mirror
has grown grotesquely large

This new lens
Locks in place

Obscures the future
And I am able to focus

Only on what I've passed

December 11, 2014

I have a habit of building teams of oddly assorted folks who come together for a particular task. So what about a death team? Who should be on it? Well, for a beginning, I need someone to select a plot. I need a rabbi for

spiritual help and to perform my funeral. I need an attorney to see my finances pass smoothly, and docs to care for me as I move from here to there.

Michael Graves is a pleasant 35-year-old man, with balding scalp and meticulous clothes. He listens heavily, reacts slowly, enunciates carefully. Last time we visited Spring Grove Cemetery and talked with Michael we got this far: Joanne wants to be cremated; I want to be buried in a pine box. Joanne wants her ashes by a serene waterfall; I'd like to be in the woods. I want a Jewish ceremony; she is ambivalent about ceremony in the first place. And of course we want to lie next to each other for eternity.

Michael listened as we disagreed. Then Joanne and I suddenly came up with the same idea. This whole thing was uncannily familiar. It was like choosing the right campsite when we went camping. Was it for the view, for privacy, for access to water, for level ground? We invariably disagreed. But we found ways to compromise, and so we did on this campsite too. Michael found a way to place the Jewish pine box on a sturdy base so it didn't sink when I disintegrate, while Joanne's urn could be in the earth next door. Joanne decided that the person who goes first gets first choice of campsite; I thought we might come in from the woods and occupy a more conventional spot closer to the entrance so on the odd chance that someone might want to visit us, they could find the site. But as Michael took us to the ground we had chosen Joanne became alarmed. She noted that the headstone next door announced our neighbor as an avid NRA enthusiast. We would have to take the lot near-by, to be free of other worldly rifle shots.

December 18, 2014

I have two questions. What are the moments preceding death going to feel like? and what happens at the moment life goes out of me? What do I become, where do I go when I no longer inhabit the body I have lived with for nearly 80 years?

For the first question, I feel assured from Dr. Cogent that he will be with me to the end. For that I am grateful. For the second question...

It is time I met with Rabbi David.

Br'er David is a large burly man with dark curly hair, a winning smile, and a broad expanse of presence. As his arms open to embrace me with his "bear-hug", I worry how our bodies are going to fit. Does he see how much weight I have lost? My thin frame must fold around his protruding mid-rift. If he squeezes too hard I will break.

I survive the bear hug. We chat briefly together with Joanne, then I invite David to my study, where we settle into comfortable chairs.

"What happens when we die Br'er David? I mean what happens at that very moment when our blood runs cold and life disappears from our body?"

David sits back, taking in my question as though it were delicate food that needs to be digested slowly.

"Death frees our soul," he says finally. "Our spirit goes where it has always gone, to the people whom we have touched in the course of our life. What happens after that no one knows for sure, but that we inhabit the souls of others, that we, even after death, connect, is true and fundamental."

Souls connecting with each other. I hadn't quite thought of it that way. It is a comforting view of the moment of death, of passing from one state to another.

Further, by applying the idea to my present situation, this perspective offers a direction, even a prescription for my behavior. For as I approach death, there are needs to re-connect, to tell those I love, "I love you," to address outstanding tensions, to explore future decisions, to free up the passage way before and during death, from spirit to spirit, from soul to soul.

We close a loop today in order to open a gate for tomorrow.

I ask David to perform my funeral.

He sighs deeply, "Of course I will. It would be my honor."

I feel a burden lift. It is as if new energy has infused my worn out body. My arm rests on David's shoulder as we walk, for me, briskly to the door.

Joanne remarks privately after he has left, "I've never seen two people so excited about dying as the two of you."

February 1, 2015

Plan for a Day in Congestive Heart Failure

Don't rush
Sleep any way you can whenever you can
Get back to people
Say Thank you
Do or plan a mitzvah*
One event is plenty for the day
Tell Joanne you love her

We have already signed a power of attorney, a living will; and our last wills and testaments are in order so today's meeting with Warren Bankhead is simply a question of what must Joanne do when I die? The only problem is the meeting is scheduled when I usually take a nap.

Warren takes his seat at the head of the mahogany table. That impish twinkle in his eye reminds us that the '60's juices still flow in his veins. I have trouble concentrating. There is talk about trust and trusts, marital trust, family trust, revocable trust. What does a 'revocable' trust mean. Does it mean anyone can change my will at any time, or does it mean I can no longer sing, which is the case as my mouth is dry and voice is cracking. Over the din I hear, "Above all we must avoid probate." I know my mind is

slipping. I can only think of school kids being put on probation for doing something wrong. “but I’ve never been on probation.”

“Avoiding tax, it all rests in the hands of the trustee.” Now in my mind trustee has become trusty, the warden’s special criminal whom others can’t trust. When we finish here will we be among the trusted or in our efforts to be free of burdensome taxes should we be counted among the convicts? Putting financial matters in order. I guess you have to trust somebody.

Definitely time for my nap.

February 14, 2015

Today I look back at my diary and note how much I have omitted during these frantic three months: there are only fragmentary entrees for: re-marriage of my oldest son, birth of a new grandchild, 50th birthday of my daughter, presentation together with my students at a national convention, learning my latest paper is to be published in the fall, learning my youngest daughter is to be married in 18 months. I even omit from the diary that the very day I learned of my fatal illness, was the same day I read a budget at the Literary Club.

Finally, a metaphor gives shape to my disorder.

It is as if November 24 marks the collision between two tectonic plates, life and death.

My diary entries are like riding the surface of this fault line, trying to find balance in the midst of an earthquake.

February 15, 2015

I pass this strange guy as I exit the bathroom.
He looks at me, but I do not recognize him.
Presumptuously, I take a moment to stare

“No meat on him,” that’s what my mother would say.
Broom sticks for arms and legs.
Well, he was skinny at best then.
But then he weighed thirty pounds more than now.

This guy I’m looking at
There are no muscle contours around his shoulders just pointy bones.
Pectoralis deltoid triceps all of them disappeared.
Ribs covered with taut skin
An uncanny likeness to inmates at Auschwitz

I see what his face is saying
Etched lines around his mouth all point downward,
wrinkles and lips spell despair.

Jack, this image of you in the mirror will never do.
How dare you drag it with you all day
It’s not even breakfast yet.



February 18, 2015

Elizabeth Kubler Ross says we bargain when we learn of a fatal illness. I thought I was immune.

My inclination toward the scientific method has become infused with magical bargains. I daily chart my weight, blood pressure, pulse. I count the number of deep breaths it takes me to regain normal breathing after I climb a flight of stairs. It used to be 6, now it's 20.

I walk a mile on the stair-master but no longer count how long it takes. I walk downhill to Mirror Lake, but ask Joanne to pick me up at the bottom, as there is no way I can make it back up the hill.

My unconscious bargain is if I exercise and keep careful records I will remain alive so I can continue to report on my "science" experiment. But all the indicators move gradually in the wrong direction.

I keep up the charts, doing my part of the bargain He never made.

February 20, 2015

I apologize. Once more the chronology of this diary is screwed up. It is time to fill in my cryptic notes about this other gnawing matter I'd rather ignore, my medical diagnosis. Once more I return to the hectic days of December.

December 2, 2014

We are trying to get our heads wrapped around this diagnosis, cardiac amyloidosis. They have already told me that it is fatal, and that there is no FDA approved medication. So why bother with a big work-up?

“Well, it’s not quite that simple,” says Joanne who has had her head into the Internet ever since day one. “There are different types, and depending on the type there may be an experimental treatment, at least something that will slow down the illness.”

I am in a different mind-set. Why is that so important? They know I have a fatal illness from the MRI, why all the fuss about a tissue diagnosis? Do they want to make me miserable carving me up until they find the amyloid? Is it so they can offer a treatment that won't work? All this unpleasantness, for what, a few more months? Or is it so insurance will pay the bill?

Meanwhile there is no convincing Joanne of the wisdom of my well-articulated “head in the sand” position. She has looked all this up on line.

“Sometimes the amyloid comes from bad cells in your bone marrow,” says Doctor Earnest, a young hematologist whom Dr. Cogent recommends. Dr. Earnest seems a little older than my grandson. He is careful to explain to

an old-timer like me how medicine has advanced. The bone marrow biopsy, he assures me, should not be unpleasant.

Dr. Earnest, carefully bores a small hole in my hip and draws marrow from my bone, not so harrowing as I had feared, but not exactly what I enjoy doing on a Tuesday afternoon.

December 9, 2014

No bad cells found.

“Maybe amyloid will show up in a biopsy of fat tissue,” he says.

You have to be kidding; I don’t have any fat tissue, and what little I had, I lost when I became sick.

December 16, 2014

“No problem,” says the general surgeon, as he carves my shrinking belly. He cuts before the Novocain has taken effect. The pain is worse than the bone marrow, and the results, just as negative.

December 22, 2014

So Dr. Earnest says, “we come to our last option, we need to biopsy your heart.”

Biopsy my heart! How the hell do you do that? By driving a super-sized needle through what’s left of my chest wall and into my heart? “I just had an angiogram a couple of months ago. Doesn’t that count?”

“No this is different,” he continues, “the surgeon inserts an instrument through a vessel in your groin, pushes it to the middle of the heart and while there grabs a few (actually 5) chunks of heart tissue which we will send to laboratories for analysis. You won’t feel a thing.

Maybe this makes sense to you, but it sounds very dangerous, and of dubious value. How many times do I have to expose my neck like a gazelle, before the devouring lion of modern medicine?



December 29, 2014

This time the tissue is positive. Now it’s official. I have amyloidosis of the heart. One by one the heart biopsies come back. It’s not this type, it’s not that type. Four of the five biopsies are back and we still don’t know what rare form of this rare disease I have. “Perhaps the offending blood cell is hiding,” reasons Dr. Earnest. “We should start chemotherapy now.” I am game, anything for the home team. Oops, while I am in his office the last biopsy comes in. It is from Mayo Clinic. I have TTR amyloidosis, mutant wild type. “Oh,” mumbles Dr. Earnest under his breath, “that must be the rare type where the patients died so quickly in our study.” Let’s send you to Mayo Clinic.

Up-date on Jack Lindy’s Health Sent to Colleagues

February 24, 2015

Jack and Joanne just returned from Mayo Clinic. He has trans-thyretin or TTR amyloidosis, “wild” type. This type is not amenable to known treatments. On the positive side, it progresses more slowly than other forms

and tends to stay localized in the heart. He was to be a candidate for an experimental protocol at Mayo Clinic involving a new drug, but that study has been suspended. Meanwhile an atrial flutter was treated with cardioversion.

Jack's major symptoms are shortness of breath and fatigue. He will discontinue his office next month.

March 5,2016

The "end-of-life" cards start pouring in. Thoughtful reflections, usually upon some small incident I barely remembered, when without self-consciousness, I offered encouragement, shared an insight, behaved in concordance with someone's ideal, contributed to a turning point in another's life journey. What a treasure chest of unintended consequences.

I pause, opening yet another card, how low can I get, being a voyeur at my own funeral.

Yet, to ponder what we have meant to people, it's something we don't ordinarily do. The cards carry so much more than I would have anticipated, and provide me with so much more to be thankful for.

Of course, just as at funerals, some of the coarser elements in my character are mercifully not emphasized. These same folks could have had fun roasting me, but not today, not in these notes, these notes about the silent ways we touch even those we think are far away.

March 10, 2015

Dear Jack,

I received the e-mail regarding your health. I am very sorry about your illness. A colleague of mine at Indiana University is expert and a leader in the field of amyloidosis associated with mutant and wild type transthyretin. I would be very happy to connect you with him.

I do not mean to be intrusive, but I felt that I should inform you.

Best regards,

Dino Ghetti, Chair Dept of pathology, I.U.



Has God been listening in on this, or did He just say to all those who were praying for me to settle down, "Here, I'll give you something to keep you quiet for a while. I have a lot more important things to attend to than this guy Lindy's health."

March 23, 2015

Dr. Donald Quixote is all we had been praying for. Yes, he is conducting a trial of a new drug for cardiac amyloidosis. Yes, I am eligible for the study. No, there will not be a placebo group. Yes, we can obtain baseline measures and begin in one week. I am to be subject number 7 of 10 subjects. Other subjects fly in from far away. Joanne and I can travel to Indianapolis in two hours.

And Donald Quixote knows all there is to know about amyloidosis.

Donald's eyes twinkle as he bonds with us. Ever keeping things in perspective, he comments, "Oh I wouldn't worry about your heart rate, you should see the rats when their rate goes up to 700 beats." Or, as I struggle learning how to give myself the viscous subcutaneous injection of his space

age meds “if you think that’s hard, you should try to give that dose to a squirming mouse.”

Touching my ankle on examination he says, “Oh, you probably do have amyloid in your peripheral nerves, it was right **there** on the last guy I autopsied.”

Dr. Quixote explains to me how an anti-sense oligonucleotide works, “It blocks the formation of transthyretin, by impacting messenger RNA at the gene level.” Frankly this space age medicine leaves my head spinning.

His nurse teaches me to inject the medicine below the skin in my belly when I read the drug’s name, ISIS #420915.

“ISIS, This can’t be the name of the pharmaceutical company,” I say.

“I’m afraid that’s the right name,” says Donald. They tell their telephone operators to slur the name and accent pharmaceuticals.”

So the new phase of my illness begins. Each Friday I inject a little ISIS in my belly. Each Saturday I feel like hell. Then gradually over Sunday and beginning Monday I begin to feel human again.

Where to from here? Hey, I’m starting to feel well enough to fill in some of these Diary entries.

April 4, 2015

I am overwhelmed at the Passover tonight. I need time to digest it before making an entry.

April 18

The Lord is going to have to shepherd this Passover. I am in no shape to lead it.

As I look out over the table so beautifully laid out and smell the food we will soon take in, I think this is an evening that *shall not leave me wanting.*

But no sooner do I begin speaking than a pall falls over the room. No matter what my words, I am dying. And it is *as though all of us are walking in my shadow of death.*

This will never do, I say to myself. This is going to be an evening of pleasure and fun. I *fear no evil*, as I have all the confidence in the world that the “kids” will rise to the occasion. I want to shout, “Hey guys, I’m not dead yet.” But instead I ask Joanne to say the blessing over the candles, then turn to my daughter Rebecca to get this thing started. And start it she does.

Rebecca *takes a straight path* explaining the meaning of the traditional symbols: Then she introduces two extra symbols: the olive for peace, for respect for Palestinians in their quest for dignity, and in our bond with all who are oppressed, and the orange, to mark our commitment to equality of women. (An Orthodox rabbi reportedly said that the day there will be a female rabbi is the day there is an orange on the Sedar table.) With this the table comes to life.

Ben looks to his three month old son, Aaron, as if he is to ask the four questions. Of course silence follows. We wonder where this silence will go. Ben slowly removes his son’s handsome top. Emblazoned on Aaron’s are the

words, “Why this night different?”. Everyone laughs and Aaron’s broad smile mirrors the happiness we all feel.

Tanya signals us to contain our rambunctious behavior as only a kindergarten teacher can. She distributes i-pads around the table. Suddenly the story of the Exodus flashes in front of us in the media of our new age.

Dan crisply moves us from kindergarten to graduate school as he turns the table into a discussion group for advanced Talmud students. With a wry rabbinic smile he seems to say “yes, your answer is a good one, but not quite good enough. How do the ten plagues apply to our contemporary world, what do they say about the scourge of humans’ capacity to endanger each other and the planet? And what must we do about it?”

Rachel assigns us to four teams: frogs, lice, locusts, and wild beasts. Each group has to perform a choreographed cheer. Then the teams compete answering questions about Passover, all to gain added seconds, so their team will start the search for the matzah before the others.

I can feel that *all gathered here tonight art with me*: Joanne, my children their spouses, my grandchildren, and those whose spirits I feel but who are no longer physically with us: It is as though an invisible *rod and staff guide* us. I am thankful for the *green pastures* that have somehow nourished each child.

I look about the room. Such joy, wit wisdom and love, such *a table before me*.

Past the din of surprise and laughter, I step back. I realize: here is my family, together with me tonight as surely as they will be together with me the night I pass from here to there.

Truly, *my cup runneth over*.

Surely goodness and mercy shall follow me all the days of my life. And I shall dwell in the house of the Lord forever.

May 30, 2016

W.H.Auden wrote: "Let your last thinks all be thanks."

May 30, 2016

Oliver Sacks says it this way

“There was an intense emotionality at this time: music I loved, or the long golden sunlight of late afternoon, would set me weeping. I was not sure what I was weeping for, but I would feel an intense sense of love, death, and transience, inseparably mixed.”



June 16, 2015

During my nap today, my older son called about a crisis my grandson is having.

When I learn of the event, I think of Burl Ives strutting the stage in Cat on a Hot Tin Roof, protesting the way his family ignores his dying from the un-nameable scourge cancer. In this day of perhaps excessive truth telling about end of life information, what we face is different. Yet I sometimes feel like Burl Ives. My son explained to Joanne, “I don’t want to disturb Dad.”

She said “he’s taking a nap.”

As a result I am in the dark. In the hours that follow I exaggerate the event as a step towards de-personhood, and picture myself storming about, crying “mendacity, mendacity” (you are treating me as if I am already dead when I am very much alive).

Yet of course, in my storming, I ignore the vast differences between Burl Ives’ situation and my own. And I ignore that I am the one who has given the double messages: ‘don’t disturb me when I am napping’ and ‘include me in whatever is going on.’

I wonder to whom my lusty protest is directed, probably God.

June 20, 2016

It is not simple. The risk of taking out my frustrations on Joanne, my intimate partner in all this. She is getting cabin fever. She wants to travel. I want to stay at home, to stick with the familiar. I wonder, have I been sitting on the bench too long? Over my gentle protest we plan a weekend away.



November 24, 2015

Today marks one year from the date Dr. Cogent advised me I likely had twelve months to live.

The titer in my blood serum of trans-thyretin, the protein that lays down amyloid in my heart, has decreased from 21 to 5. Medically, I seem to be stabilizing. Joanne and I now refer to this as my “new normal.”

I am so grateful for this year of living, both for the moments chronicled in the journal and the many more moments not chronicled but experienced more fully than any year I can remember.

As to further entries, who is to predict? The pages remain open

May 15, 2015

The Task (tafkeed)

Your youth, my age
Your health, my frailty
Together we meet

Death's mask penetrates horizon
Transfiguring time into sacred space

Unveiling deepest dreams and goals
Choices and directions

Requests for blessing
And for caution

Am I up to the task
I and Thou?

To listen, Sh'ma
To understand, L'havin
To speak, L'Daber

For life, L'chaim

January 19, 2016

Today is Joanne and my 37th anniversary. How grateful we are to mark this day together. Yet, oddly neither of us wants to make a big deal of it. A year ago every marker in the calendar was the last. This year, though we dare not say this out loud, there may well be more.

My health is stable. I write, I read, I practice the piano. I exercise with Tai Chi rather than tennis. I nap, and I stay in contact by phone with

family and old friends. Joanne and I visit our new grandson; we watch Doc Martin and Foyle's War to escape, and Breaking Bad for black humor. I try to go to Literary Club when I am up to it. And we host friends and family who come by to visit. Occasionally I am invited to speak. It wears me out but I feel good about having done it. I am so fortunate to have Joanne by my side.

Life is good.

March 18, 2016

Today marks one year of taking ISIS 420915. I visit Dr. Quixote. Good news. All the markers indicate my holding steady. No change in thickness of wall of ventricle, of course, moderate heart failure remains.

I can look forward to many more months.

On the night of good news, I dream I am at a picnic. I am dressed in a gray shirt. Mother says that is the wrong shirt to be wearing. My brother Phil, is running holding a delicious sandwich. I want some. I run after him but he is too fast. I yell, "stop, I have a bad heart." I then awaken, screaming at Phil for not stopping.

On reflection I realize that not only are my mother and brother dead, but also the others in the background of the picnic in my dream, are cousins and friends who have recently died. So, the setting for the dream is apparently an afterlife picnic. The "good news" I received yesterday about my medical condition, has evoked a paradoxical disappointment, that, for now, I am to be excluded from joining family and friends in my afterlife "picnic".

We do our best to prepare for what we think will happen next. Then comes life with all its unpredictability.

Edges

This dawn I peek by his window.
Up, alarm already off,
Quickly shaved and showered,
He ignores my presence
He rushes for appointments too important to be pondered
He gulps his breakfast
Guns his car
Attacks problems
Achieves goals
Til unwittingly he finds no breath
And sudden exhaustion

He looks at me, overwhelmed.
We have been at war this day
He and I

Only doing
Has left no room for being

I watch, another day,
He slumbers past my first rays
Awakening naturally.
He sits just outside time
Contemplates dreams not quite remembered

In a haze and in no particular order he
Brushes teeth,
Uses the toilet,
Checks his weight,
Turns on his razor,
Swallows seven pills,
Washes his face.
The haze gradually lifting
He takes his blood pressure, pulse and oxygen reading
Then sees if he can remember the numbers to write them down.

This day he practices Tai Chi.

I watch as he reaches skyward, breathes deeply, expires slowly
Visits his struggling heart and lungs.

One maneuver begins with hands extended loosely, palms down
One hand gently circles waist high, then presses down to earth
While the second hand reaches up to sky.

He pauses,
These are the things for now,
One touching earth with its rough texture,
A chore he'd rather postpone
The other a higher calling,
Something new, to create or give

These will be the actions of his day
A chore
A poem
A mitzvah

We are friends, he and I
Each of us not so much doing as being

I complete my paper on the year that was to be my last to live. But it turns out to have been a very special twelve months *to live*, full of connections, adventure, humor, joy, sadness and gratitude. And as you can see, twelve months became twenty-four. Indeed I am very much alive two years after learning I had a condition that should have killed me long ago.

It appears I have lapsed into extra innings. Perhaps more on that a later time.