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# Lessons from the Angel of Death

by William G. Bartholome

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In June of 1994, my life was visited by a teacher, the likes of which I had never previously encountered. From this teacher I have been taught lessons in a way that I had never learned before. I have come to know things about myself, about my profession, and about this society that I never appreciated before. The mentor that has been part of my life and so powerfully teaching me since then has been cancer, specifically, metastatic adenocarcinoma of the esophagus. From the time of my initial diagnosis, we have regarded this as a terminal illness, and have attempted to live our lives up against that reality for almost five years.

For those of you who know anything about Stage IV adenocarcinoma of the esophagus, that doesn't make any sense at all. People who undergo no treatment other than palliative surgery for this type of metastatic cancer simply don't live for five years. So, ours is a very unusual situation. We have been provided a rare opportunity for learning, for discovering.

Obviously, I've learned through the illness experience. I have learned in the way that one learns by being embodied and ill at the same time. I've learned about what illness means in a way that I couldn't possibly learn from textbooks or professional journals or even by carefully listening to patients and families describe their illness experiences.

About six months after my initial diagnosis and surgery, I wrote a short story called "A World Unraveling." I hoped to convey in the story something of what happens when a person is given

the diagnosis of a terminal illness; I wanted to describe the changes in that person's life and their world. I also wanted to describe the process by which the person's world first unravels and then begins to be reconstructed anew on the other side of the diagnosis. Since then I have become aware that there is very little overlap between my world pre-cancer and my world living with cancer. What I would like to share now are the lessons we have learned over the past five years during the construction of our post-cancer diagnosis world. It—the story—is an autopathography that focuses on the lessons learned primarily by the protagonist, his wife, children, and family.

## Lesson 1 — The Value of Dying

We physicians have come to think about giving a patient the news that they have a terminal illness as something horrible. We call it breaking bad news. We resist taking this step as long as possible. We talk about it as something that is potentially destructive of people. It destroys hope, we say. We ask: "Will this bad news put my patient into a tailspin of rapid deterioration; will she go on to die simply because I have destroyed her hope for a cure by telling her that she is terminal?"

I think that perspective fails to capture the idea that knowing that one has a terminal illness, knowing that one is dying, can be extremely valuable information. Yes, it involves major stress, and it will precipitate radical change in the patient's world. Everything may change, but that doesn't mean it's not an incredibly valuable thing for one to come to know. Its value can be talked

about in a variety of ways. We could, for example, talk about people's right to know the truth about their situation. We could talk about people's need to know. We could focus on the fact that people who are informed about their situation are more likely than anyone else to understand the value of Advance Treatment Directives and appointing a Durable Power of Attorney for medical care, and they are more likely to understand the value of discussing their "DNR status" if they are ever admitted to a medical facility. The patient or family may even want to have a pre- and post-hospital DNR order to protect him or her from inappropriate CPR in the home.

We could talk about the fact that such patients are likely to consult with their attorneys; to complete wills so that their estates don't end up in probate; to consider setting up living trusts and other means of protecting assets from onerous inheritance taxes.

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We could discuss the need for the terminally ill patient to establish relationships with palliative care/hospice professionals and programs to address special healthcare needs, and to renegotiate ongoing relationships with healthcare providers. Such patients need to explore with their healthcare providers such fundamental issues as the almost unique goals of medical care in the care for a dying patient. Yet, it is clear that none of these vitally important issues are addressed unless the person is informed that he or she has a terminal illness.

Our experience during the first six months, although extremely dominated at times by grief

work, was that it was okay and it felt good to have this information and we did a lot of planning. We did a lot of planning and thinking to anticipate problems that were coming down the road. But we also made some decisions in the face of our terminal illness that we consider in retrospect to be very important decisions. For example, we were engaged to be married six months prior to my diagnosis. We got married six months after my diagnosis. And if people ask me what's the one thing you've done in the past five years that might have accounted for why you're still here, I would say that it was getting married, hands down, no question about it.

We also packed a lot of living into that first year. My daughter Sheila decided that she wanted her old man at her wedding. She had been engaged. She decided to get married, too, and did so, three weeks after we did. We decided to create a home together. Pam had her house; I had mine. We decided, what the hell, we'll hire a really good real estate guy and tell him that he's got three months to sell her house, my house, and find us our dream home. And we hired this guy, and he did it. It was amazing. The biggest problem we had was with the banks. Everything else fell into place with a minimum of problems.

Well, while we were engaged in all that living, it suddenly dawned on us that a whole year had gone by, and here we still were, feeling pretty good, with fairly minimal symptoms, mostly recovered from the surgery and the effects of the surgery. And — of more importance — we both started noticing things that were very different about ourselves — we had developed different priorities, different values, and different ways of doing things. I made the observation one day that I liked the person I was becoming better than I had ever liked myself before. Although my life was very different, I liked living in this new, after-cancer way. One example, I was living in the present. Somebody takes away your future, it tends to focus you and what it focuses you on is not the past. What it focuses you on is the present. I felt that I had been given a chance to do something that we Americans seldom do: to live fully in the present. It was about

that time that I decided that I was so impressed with what we were learning that I was going to write it down and try to publish it in hopes that other people might be able to hear some of what we had discovered.

So I wrote a meditation called "Living in the Light of Death." What I tried to build into that text was the idea that living in this way, living in the way we were living, may actually be the best way to live, the fully human way to live. Perhaps living a life enlightened by death is a better way for people to be in the world.

## **Lesson 2 — No Space in Our Lives for the Dead**

About that same time lesson number two came along when one of my closest friends experienced his visit from the Angel of Death. I've titled it: "No Space in Our Lives for Our Dead." For several years, I had been part of a men's discussion group. We met at least monthly, went out into a prairie preserve, usually cooked breakfast for each other, and sat around talking. Our purpose was to explore spirituality, and we met on Sunday mornings, but usually all we did was lament our lack of a spiritual life. Well, obviously, once I got diagnosed, my situation became very much topic number one of this small group and whenever we got together that tended to be what we talked about.

And in talking about my death we realized that we were actually talking about something intensely spiritual for the first time. Well, we were meeting regularly when in late December I got a call from the wife of one of the members who informed me that her husband Bill had died suddenly and unexpectedly at home. He had a long-standing cardiac arrhythmia problem, and the presumption was that he had suffered a fatal arrhythmia that morning.

Needless to say, having somebody ripped out of your life when you're dealing with the situation that we were dealing with was not easy. I found it very frightening. Bill had repeatedly assured me that he would be with me in my dying. At Bill's memorial service, death taught me a lesson. We, a group of about thirty people, had gathered in Aiken

Prairie, just east of Lawrence, Kansas, to scatter Bill's ashes. We stood in a big circle, sang songs, said some wonderful things about Bill, and then Bill's widow opened up a deer skin in which his ashes were being carried and started spreading the ashes out into the prairie, but she did something that none of us had anticipated. She invited us to participate in the scattering of the ashes.

I don't know how many of you have done that. I had never done it, but everybody else was doing it so I lined up to do it as well. I got my handful of ashes, went off by myself and sprinkled them in the prairie while I was crying about Bill. Then I noticed that my hands were covered with this very fine powder, human ash, Bill's cremains. Although I briefly considered wiping them off on my jacket, I realized my jacket would be covered with this fine powder. Suddenly the solution came to me—that I should go off by myself, kneel down, and while

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kneeling, just sort of surreptitiously wipe my hands on the grass. So I went off by myself, knelt, and leaned down about to wipe the ashes off my hands when a voice inside me said, "Don't do it. Don't do it." What am I supposed to do? I asked. "Take him with you," was the response. How in the hell am I supposed to take him with me? I have to drive home. I've got this powder all over my hands. How can I take him with me?

Solution: lick your hands. I licked the ashes off my hands. As I was doing that, I said to myself, "Damn, you're taking Bill into your body. His atoms will become part of your body, part of the calcium of your bones. You will have his atoms mixed with yours until the day you die. You will have him with you in a way that you never imagined possible."

As I've shared that story with people, I've become aware of how little presence there is in our lives of the people who have died. And I've come to believe that one of the things that makes it really hard to die in America is that you know when you're dying that once you're dead you're out of here. You're forgotten; you're gone. It seems that few members of this society have any room in their lives for dead people. We don't have places in our homes that honor our dead. We don't talk to our dead. We may once a year visit their marker out in the cemetery, but they're not present in our everyday lives. They have no power to influence us in any way, because we don't keep them alive in our minds and hearts. I think that's tragic, and I think it speaks volumes about our society and about how difficult our society makes it for people who are dying.

The only way that I believe that I will survive my death is if you who are reading this keep me alive in your minds and in your hearts. Otherwise, I will be no more. It's up to each and every one of you to decide whether I will be present in your lives. You can have as much of me as you want. I have dead friends who are more a part of my life now than they were when they were alive. I have a little shrine to Elizabeth Layton in a corner of my office and I talk to her every day. Well, before she was dead, she lived in Wellsville, Kansas, and I talked to her twice a month.

### **Lesson 3 — Limitations of the Hospice Solution**

As I was looking at my own death and wondering about how I would die and where I would die and what I would need and what Pam would need and how it would all shake down, I became convinced that there was one thing I knew about this business of dying in America. In twenty-five years of working with dying children and their families I had come to know that there is one group of people who are seriously pursuing this idea of caring for the dying in the United States. It is the people who have been part of the hospice movement for the past twenty-five years.

So I became convinced that my dying was going to take place under the care and support of a hospice and that I was going to avail myself of this

wonderful mechanism of getting myself and my family necessary care and support. However, as I began to arrange for this support, I began to learn a lot about hospice in America and what is happening here. And I am convinced that the hospice solution to the problem of dying in America is profoundly inadequate. It's not going to work, at least not the way we have it structured right now. What's happened?

What's happened is that what began as a social movement in which volunteers and volunteer professionals played the major role in providing care for dying people has been transformed into an industry. When hospice was forming as a countercultural alternative to mainstream health care, money was the last thing that people worried about. Sure there were bake sales, car washes, and other kinds of fund-raisers and solicitations aimed at keeping a little bit of money coming in the door. But there was little if any billing or concern about reimbursement for services by third-party payers.

That changed in 1983 when the United States decided that hospice had come of age and what we needed was a hospice Medicare benefit. So the leaders of the hospice movement including the fledgling National Hospice Organization sat down with the people at HCFA and designed a hospice benefit for the Medicare program. The creation of this revenue stream has radically transformed hospice into an industry. There's actually a significant for-profit presence in hospice in the United States today. Hospice care has become part of the medical industrial complex and it has radically changed to the point that a lot of people who have been part of the movement for twenty years are disgusted with it and are getting out. And other veterans of the movement are trying hard to figure out how to reclaim something of the character of the original movement.

There are a number of problems with this development. Let me mention just two. One is that the hospice benefit as it's set up now requires that patients be certified as terminally ill with an estimated six months to live before they can be admitted into a hospice program. There are some really serious problems with that. One problem is

that some physicians, not a majority, but clearly a significant minority of physicians, never have terminally ill patients. They don't believe in it. If you're their patient, you're either sick and in need of no-holds-barred medical care or you are dead and beyond the reach of medicine. Another problem is that the revenue stream has locked hospice into a little niche and only about 15 percent of the Americans who die each year are being served by hospice. That means 85 percent of us get nothing as we die, while 15 percent of us get Cadillac treatment. It's a haves and have-nots thing. The people who have homes, caretakers, health insurance, and access to lots of social resources; the people who could probably do fairly well without hospice services, are the people being served. People without these resources are not being served. It's crazy. Something has to be done.

#### **Lesson 4 — Physician Duties Owed to the Dying**

We as physicians should step up to the plate and take on our responsibilities for these problems. One thing that we could do, particularly if we are primary-care physicians, is let patients know when they are dealing with something that is life threatening, when they are dealing with an illness that might very well be the illness that "takes them to ground."

It's interesting. If you look back into eighteenth- or even nineteenth-century America, delivering this message was one of the most important roles that a doctor played in the life of his patients. The doctor and the patient engaged in a very formalistic "ritual of warning." You've read about it. You've probably seen it in old movies: a darkened room, the patient on one side of a big desk, often holding hands with his spouse; the doctor, on the other side of the desk shuffling through papers. The doctor looks up and says in a very solemn voice, "John, I'm looking at your lab work here. And, as your doctor, it's my obligation to tell you that it's time for you to get your affairs in order." If primary care physicians reclaimed that cultural ritual as their duty, we could eliminate a major part of the problem. We would eliminate those Americans who die without ever knowing that they're dying,

without anybody ever telling them that they were up against a terminal illness.

To do that, we need to know when patients are terminally ill. Interestingly enough, that information is now at hand for a wide variety of disorders. Some cases are crystal clear. If you have renal failure, whether you go on dialysis or not, you have a terminal illness. You have no kidneys. That's terminal. There's no way around that. Even for a transplanted person, it's an interesting question. Whether they have a terminal illness or not, they are at least at risk of developing life-threatening rejection or something like that.

We actually have pretty good criteria for identifying within populations of patients those who are at a very high risk of dying. We're not very good at the time frame, however, and this business of the six-month interval has got to go. Yet that's not the major problem. The major problem is simply

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that terminally ill people don't get identified and referred to hospice in a timely enough fashion. Even this year, 15 percent of all the patients referred to Kansas City Hospice died within forty-eight hours of their referral. You can't do a lot of hospice care in forty-eight hours.

It may be an ethical obligation not only for doctors to engage in this ritual of warning, but also to make sure that the patient has access to

appropriate palliative/hospice care. A Physicians Advisory Group to the Pathways Project of the Midwest Bioethics Center has developed a wonderful short text outlining a physician's promises to patients facing end-of-life issues. One of these promises is to talk to the patient about hospice care. Not only will these doctors determine when you have a terminal illness and help you discover the value of wearing the label "dying patient"; they will also sit down with you and help you plan to get appropriate palliative or hospice care. There are a couple ways of looking at that aspect of lesson four. One way is to think about dying without hospice care as a lot like undergoing major surgery without anesthesia. Not the best way to go by any stretch of the imagination.

Another way of understanding lesson four is to examine the possibility that physicians may be dealing with patients who are going to experience the last chapter of their lives in much the same way as I have experienced the last chapter of my life, namely, that it's categorically the best chapter I've ever known. Clearly one of the things that has made it the best is that I have shared it with Pam. But it is also richer and fuller than my pre-cancer living. I feel much more alive. I feel like I have evolved as a human being in these past five years in ways that I never imagined possible.

So if doctors don't identify terminally ill patients, engage in this ritual of warning, or get their patients appropriate end-of-life support, then perhaps we ought to think about what is really going on: physicians and our death-denying society are robbing people of part of their lives. Can you imagine that, robbing somebody of a whole chapter of his or her life?

### **Lesson 5 — America's Need for "Rituals of Withdrawal"**

Over the past decade, America has been dealing with "Outlaw Jack" in Michigan and a huge cultural convulsion, which reached its zenith in Oregon when that state passed legislation allowing physician-assisted suicide for the terminally ill. It seems that large numbers of Americans have bought into the notion that if you want to have a good death, you either have to join

the Hemlock Society and "off" yourself; or work to pass laws that will allow your doctor to give you the assistance you need to off yourself.

I found myself asking: "Isn't this a symptom of some deeper problem?" Why is America convulsed with this technological quick fix? I came to see it as a manifestation of what some philosophers call hyper-modernity. Not just "Better Living through Chemistry," which would be modernity, but "you can only live (and die) if you get good chemistry," which is hyper-modernity. The idea that to get dead, you need to kill yourself or find somebody to assist you in killing yourself is bogus. People in other societies, in other cultures and in other times, have been getting dead without suicide or without physician-assisted suicide for a long damn time. As a matter of fact, you can get dead whenever you're ready. All you have to do is withdraw from the world, and you'll die as predictably as the sun will come up tomorrow.

A lot of old folks in nursing homes and extended-care facilities are discovering this idea and spreading it in a sort of countercultural movement. Often in whispers, they tell each other: "All you've got to do is keep your mouth shut!" Don't let them put anything in your mouth! Tear out any tubes that they try to stick in you, and you'll be dead. It works. It's a wonderful solution. Why don't we in almost twenty-first-century America have rituals of withdrawal to support people who are ready to get dead?

Why can't Hospice say to people, "If you're ready to die, come to us, and we'll help you die"? Hospices don't say that, do they? They say, "We neither prolong life or shorten life." When you're sick of life and ready to go, you want to get dead. You want to go. You've had enough. The burdens are intolerable. Do you have to kill yourself or find a doctor who will help, or can we have in our highly evolved society some of the same rituals that so-called primitive societies all over the world have developed to support people who are ready to withdraw? In not so enlightened eighteenth- and nineteenth-century America, there was such a ritual. Your great-grandmother may very well have engaged in this ritual. It was called "taking to bed."

Granny came out and announced to the family, "This is it, folks. I'm taking to bed." Then she went to bed and stayed in bed until she was dead. And everybody knew what that meant and how to behave around a person who had taken to bed. Some old people who took to bed died in days or a few weeks. Some old people who took to bed got comfortable with it, and ended up spending years in bed!

About this time I wrote my second meditation: "STILL/HERE above Ground." In it, I reflected on what we had learned during our second year of living with dying. I wrote out my own "ritual of withdrawal," how that was going to work for me. I also introduced the idea of "living by the calendar." I don't know about the rest of you, but I cannot live each day as if it is the last day that I am going to be alive. I can't. That makes life really hard for me. But what I did discover is that I can live by the calendar method; I can live in yearlong segments. I could live each day on the calendar as if it were the last time I would be above ground on that day. I could live each birthday that way, each wedding anniversary, each spring, each Christmas. And it not only worked, it actually made each of those days more special than they would otherwise have been.

### **Lesson 6 — Existential Questioning**

During our third year, one of the things that puzzled me was why I was in a place that seemed so different from where everybody else was? Why did I feel like such an outcast, such an "Other?" Pam and I were feeling very socially isolated. It's hard to start new friendships. It's hard to get people willing to invest in a relationship with you when they know your limited future and the challenges coming down the road for you. I began to resent that and to wonder about the relationship between being terminal and being mortal. An interesting question, no? What I finally figured out is that the only difference between being terminal and being mortal is the time frame. Existentially both of them are the same damn situation. Yet I, the terminal one, was living in a society of people who denied that reality, a society made up of people who considered themselves to be temporarily immortal, not

vulnerable in the same way I was to death, and yet they were, and you are. You're "mortal" to my "terminal," and it's not all that different.

As a matter of fact, I discovered as I wrote the third meditation "Are You Still Terminal?" that I wanted to be terminal for the rest of my life, no matter what happened with my cancer, because living in that kind of relationship with death had given my life a value that it never had before. There is actually a very interesting literature that explores

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what life would be like if humans were immortal. Mortality is actually a critical aspect of what makes us human. To be human requires the presence of death in our lives. Death is, as a number of philosophers have argued, what gives life its punch. It is what many have called the wellspring of life; this business of living life up against the clock. That's what gives life the force that it needs. Otherwise, there would be nothing that compelled us, that brought us to action. So the metaphor that I began using was the metaphor of death as sugar. Think about death as what adds sweetness to your life.

That metaphor didn't just drop into my head. It was placed there through conversations with people who were hospice patients, who shared with me that the time that they had as hospice patients was some of the sweetest time that they had ever known. They told me that they were more open to love as dying people than they had ever been before, that they were more capable of love than they had ever been before, and that it was death that made it possible for them to know and experience that love. I had grown comfortable with the metaphor of having death on my shoulder; death as a companion on this journey called life.

And, yet, what I discovered, the more I thought about it is, "no, death is right here inside of us." Death is the skeleton that is there in you, as much a part of you as your flesh. That's the relationship that we need to cultivate. We need to aspire to a relationship that would allow us to touch the skeleton we are becoming and to acknowledge and embrace that skeleton in each other.

### **Lesson 7 — Spiritual Hounding**

I titled the fourth of my published meditations: "May I Be A Cancerous Survivor?" Little did I know how cancerous I was as I was writing it. In the process of writing that meditation what I shared with people is that this business of my existential wonderings and questionings had actually had an effect on me that I had not anticipated. Allowing death to haunt my life opened me up to an experience I hadn't had since I was a child. And that was the experience of the presence of God in my life. When I was in high school, the poem "The Hound of Heaven," was the most spiritually awakening thing I had ever read. Why? Because it fit my experience of God. I had no idea who God was. I had no idea what God wanted from me. I had no idea how to pray. I had no idea what it meant that God existed. But there was one thing that I was damn sure of and that was that God was hounding me, was in my life whether I wanted him there or not. And there wasn't a damn thing I could do about it. I couldn't shake God no matter what I did. Hounding my life, always there, always at my head, always at my heart; hounding me all the time. So being open to death in that existential way, I discovered that I was leading a life hounded by this spiritual presence. I don't want you to get carried away with that. Notice I didn't say anything about religion.

I still don't have a clue about God. But I do have, once again, this very powerful sense of the "thatness," of the "thatness of God." My sisters had a prayer gathering at one of their homes for me

the day before I was to have some cancer treatment, and it spooked me so badly to think about going to a prayer service that I decided the only way I could possibly do it was to write my own damn prayer in self-defense. So I did. I had never written a prayer in my life. It's called "A Prayer in Celebration of our Fifth Last Christmas Together" and it's basically a prayer that tries to express what Pam and I have experienced in the last five years in terms of spirituality. Basically what the prayer says is: "Thank you, thank you, thank you, God." It expresses our gratitude for what we've had, five years of incredible joy that we never expected to have, a gift the likes of which we never considered ourselves worthy: a gift of grace.

That's the end of the lessons, seven lessons. There may be more lessons to come. As my cancer "resurfaced" with a vengeance over the last few months, Pam suggested that we needed a new metaphor, so we switched from the metaphor of "journey," to the metaphor "adventure" to underscore the notion that we have no clue what's coming. And the story of our lives from November of last year until now has been totally unpredictable. We figured out that if we wanted to engage in planning, the only thing that we could plan for is uncertainty, because that's what's in store. We are on a roller coaster ride the likes of which we have never known. So the lessons to come may very well have to do with control, with relinquishing my embodiment to the cancerous Bill. I feel like I am embodied but that the cancerous Bill is becoming the dominant partner in this dance of living/dying. The cancer seems to be leading the boy.

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