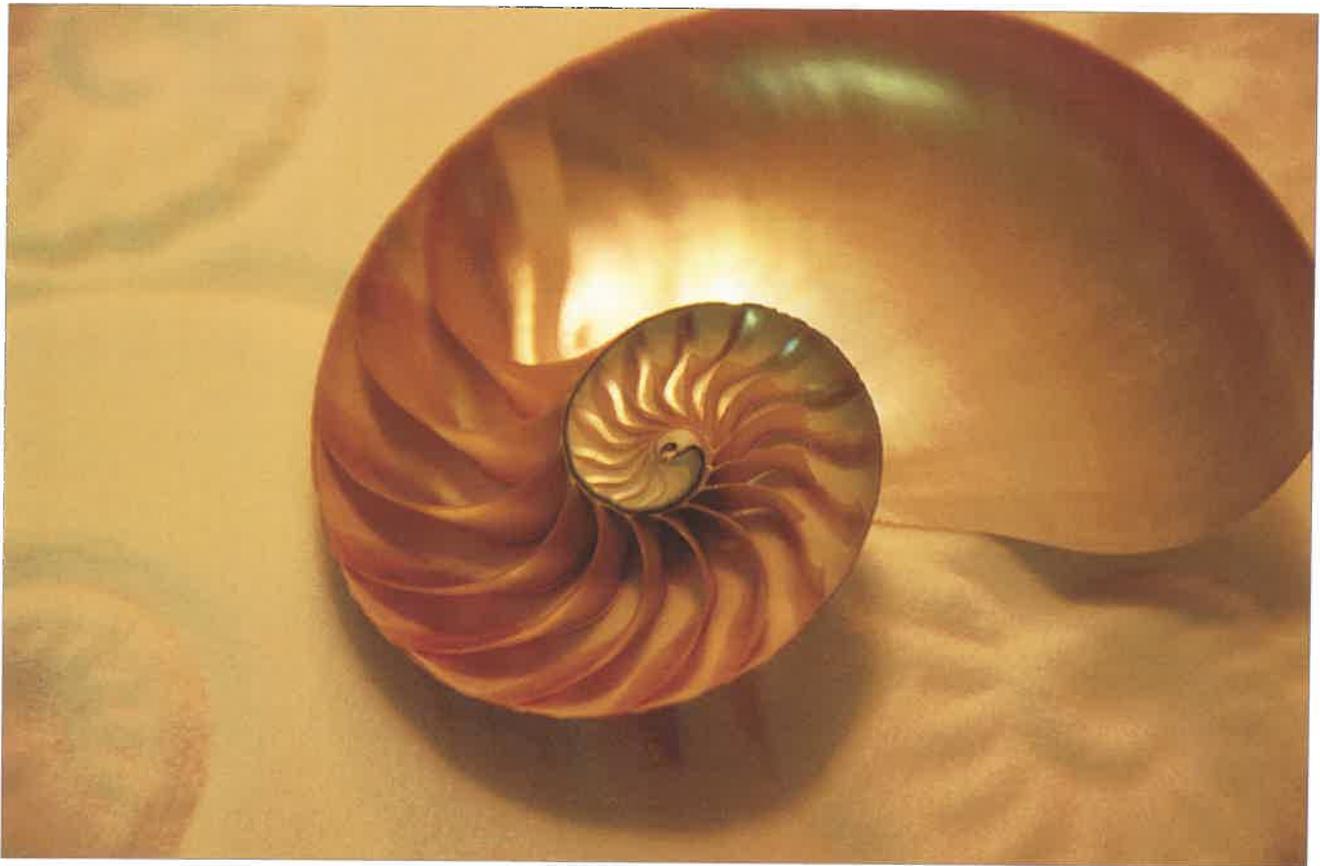


BIOETHICS FORUM

Vol. 16, No. 1

MIDWEST BIOETHICS CENTER

Special Issue



Meditations by William G. Bartholome

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Address membership requests to
Deloris Nedblake, membership director
Midwest Bioethics Center
1021-1025 Jefferson Street
Kansas City, MO 64105-1329
(816) 221-1100 Fax: (816) 221-2002
E-mail: bioethic@midbio.org
Web page: <http://www.midbio.org>

**BIOETHICS
FORUM**

Vol. 16, No. 1 • Special Issue

MEDITATIONS
by William G. Bartholome

Art

Chambered Nautilus 1 and 2
Photos by Donna Blackwood, 2000

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Editor's Note

On our cover, a chambered nautilus, a classic symbol for introspection, reflection, insight; and on each page, William G. Bartholome's record of what it is like to live in the bright light of death.

For readers of this special issue, I wish three things: a radical openness to Bill's message; a share in his unwillingness to revert to the common pattern of living primarily for the future; and time — perhaps in the "silent company" of family and friends — to plan your own rituals of withdrawal. And a fourth wish is this: that we and our communities may become, as Bill believed we should be, "some of the least death-fearful people on the globe." Midwest Bioethics Center, its members and supporters, offer their resources to help us meet this challenge.

— Rachel Reeder

BIOETHICS FORUM CONTRIBUTORS



William G. Bartholome, a Kansas City native and pioneer in the pediatric bioethics movement, was one of the first doctors in the nation to focus his work on protecting children's medical rights. A graduate of the University of Kansas, Bill completed his residency in

pediatrics at Johns Hopkins Hospital in Baltimore, Maryland, where his involvement with the "Baby Doe Hopkins" case helped set the course for his future. He also served in the U.S. Air Force; received a Joseph P. Kennedy Jr. Fellowship in Medical Ethics; and attended Harvard University for a master's degree in theological studies in ethics. Before returning to the University of Kansas, Bill served on the faculty of the University of Texas Medical Center in Houston (1976-1983), and taught pediatrics and clinical ethics at Lutheran General Hospital in Park Ridge, Illinois (1983-1986). He was on the board of the Kansas Committee for the Humanities from 1988 to 1994, and a member of Midwest Bioethics Center's board of directors from 1986 until his death in 1999. The gifts and challenges of his involvement remain with us forever.

Myra J. Christopher and **Don F. Reynolds** are on the staff of Midwest Bioethics Center.

Preface

In June 1994, Bill Bartholome was diagnosed as having metastatic adenocarcinoma of the esophagus, an invariably lethal cancer. Nearly five years later, in his next to last public remarks about what he'd learned as a dying person, Bill said that his was "a most unusual case." He meant, I think, that he had lived longer with his diagnosis than was believed possible, and for most of that time he had been relatively free from symptoms of the disease. For those of us in the audience that day — and for those who read these *Meditations* — the most unusual aspects of Bill's case are not its physical dimensions. The most extraordinary aspect is what Bill made of the last chapter of his life.

Bill was fifty years old and a national leader of the bioethics and pediatric medicine communities when he received his diagnosis. In the mid-1980s he had returned to Kansas City to join the faculty of his alma mater, the Kansas University School of Medicine, and to become an officer, director, and unpaid staff member of Midwest Bioethics Center.

If "meditations" are the ordered way that authors express themselves on important topics, and if these authors value their experience because it yields important insights and value their insights as grist for what they teach, then this collection of Bill's meditations was inevitable. Inevitable, because Bill's appetite for experience fueled his drive to learn . . . and Bill was one great teacher.

In December 1994, Bill wrote the first of his five “last Christmas” meditations. Alone, each meditation is an eloquent statement filled with insight and written with clarity. Taken as a set, they are a time-lapse snapshot of Bill’s encounter with what he called “the mystery of life-death.”

In his last lecture, and in his last correspondence with me, Bill expressed his wish to be remembered. I hope each copy of this issue of *Bioethics Forum* becomes a wish-fulfilling instrument that is read, reread, and shared until its pages wear out.

Bill Bartholome died August 2, 1999.

Don Reynolds
Special Projects Director
Midwest Bioethics Center

Bill Bartholome introduced himself to Midwest Bioethics Center in early 1986, a fortuitous moment in the history of the Center.

Living in the Chicago area at the time, Bill wrote to Karen Ritchie, one of the Center's founders, and said he would be moving to Kansas City shortly thereafter. He knew of Midwest Bioethics Center, and wanted to discuss with us how he might be involved in the Center's work.

Karen and I met Bill at a restaurant in the Country Club Plaza. He was young, tall, nice looking, but my original impression of this man was that I wasn't sure his ego would fit in Kansas City, nor could I understand why he would be interested in our fledgling organization. But initial impressions aside, it was impossible to ignore the intense interest and offer of help from this pediatrician who was already well known by all of us who had studied the history of the bioethics movement.

Bill's introduction to the bioethics movement began years before, and it was truly a baptism of fire. While a pediatric resident at Johns Hopkins University, Bill encountered a situation that changed his life. It involved an infant born with Downs Syndrome, and the decision by the infant's parents to forgo a simple surgical procedure that would allow the baby to thrive. Further, the parents decided not to feed the baby, and to allow him to die in the hospital.

Foreword

*by Myra J.
Christopher*

Against the objections of the parents and the attending physician, Bill and the chief resident, Norman Fost, went to the mat on the child's behalf. In the end, the court decided with the family.

The baby was placed in the back of the hospital nursery where he lived for seventeen days, then finally died. At the time of the baby's death, Bill was on a plane with a legal document in hand, hoping to solicit support from the state court of appeals. Afterwards, disillusioned by the process, Bill went to Harvard University where he received a master's degree in theological studies.

While in Cambridge, Bill became acquainted with the Kennedy family. With their support, he went on to the Kennedy Institute as a fellow. But

While still a young physician, he was largely responsible for shifting the way we view the rights of parents to make treatment decisions for their children, and his legacy of promoting the rights of children in healthcare decision making continues to this day.

he hadn't forgotten his experience at Johns Hopkins. While at the Institute, Bill produced a compelling video that vividly and dramatically portrayed the ethical situation he had encountered during his residency. At the time of its production, the video of the Johns Hopkins "Baby Doe" case was so compelling that Walter Cronkite once showed it in its entirety on the *CBS Evening News*. It is still used today for teaching purposes. And Bill Bartholome became a nationally known name in bioethics.

Thus did Bill's work in bioethics begin. While still a young physician, he was largely responsible for shifting the way we view the rights of parents to make treatment decisions for their children, and his legacy of promoting the rights of children in healthcare decision making continues to this day.

By the time we met Bill, he had been at two prestigious ethics institutes – The Center for Medical Humanities at the University of Texas at Galveston, and the Parkridge Center in Chicago, Illinois. He and his family had recently decided it was time to return to their home town, to Kansas City. Bill had taken a position at his alma mater, the University of Kansas School of Medicine, to work with the Department of the History and Philosophy of Medicine and to do clinical ethics in the University's hospital.

At lunch that day, Bill became clearly energized as we discussed the Center's vision of a health care delivery environment anchored in respect for the dignity of patients and informed by ethical discourse. He became even more excited about the notion of "doing ethics in community." And that was the beginning of a relationship that became vital to the direction and growth of Midwest Bioethics Center. I could never have imagined that day, fourteen years ago, how important Bill would be to the Center, nor how close a colleague and how dear a friend he would become to me.

Even before moving to Kansas City, Bill joined the Center's board of directors. He was looking for a community of people, he said, with whom he could share ideas and engage in dialogue. And once he and his family were settled in Kansas City, Bill began to live his words.

Bill threw himself into the Center's work. Immediately he demonstrated that, in addition to his board duties, he was willing to do virtually anything necessary to help the organization grow. He and other founders of the Center became "volunteer staff." As such, Bill presented programs, led the ethics committee consortium, participated in ethics committee education, headed up task forces, and regularly wrote articles

for the Center's publication, now known as *Bioethics Forum*. He participated in planning programs for the community, and was always available to me as a sounding board.

In June 1994, Bill called me to tell me that he had been diagnosed with esophageal cancer. The prognosis was grim — a fifty percent chance to live six months. We were devastated; I was not sure that we would be able to survive Bill's loss. And I couldn't imagine Midwest Bioethics Center without him.

Following the diagnosis, Bill had a major operation that nearly killed him in and of itself. The day he was discharged from the hospital, I met him as he was leaving for home. He explained the "disease model" to me and told me that he would not undergo further treatment. In the time he had left, he said, he would tend to family and to relationships. He assured me that we had to go on with or without him — and that we could. And he left us all with the feeling that before we even had time to deal with this dire prognosis, a dear, valued friend would be gone from us.

Fortunately, and much to the surprise of his physicians, Bill rebounded. In the months that followed, we all began to muster hope that he would be with us for a while longer. I remember desperately wanting to imagine that his prognosis was mistaken, and that things would return to the way they had been before.

But, to his credit, Bill never let us entertain that idea for very long. Even when he attended meetings that he had led for many years, he would not take his rightful leadership place. Rather, he would sit among participants, refusing the head table. Bill's message to us was clear: "You'll be okay when I am gone; you can do this without me. It's time to start."

During the first year following his diagnosis, Bill made a presentation he called "Living in the Light of Death," which we published in our monthly newsletter. And when the next year came around, he wrote another meditation, with a new one each subsequent year. This theme — that to

have a terminal diagnosis, to be named among the dying, is a liberating gift unlike any other — became Bill's recurring message.

For more than four years, we all benefited from Bill's insights and wisdom as a dying person. He shared that wisdom with us in the form of these yearly meditations, published here in the Center's journal, *Bioethics Forum*.

And with each new meditation we began again to believe that Bill had beaten the odds. He was cured. He would outlive us all, we said jokingly.

Just before the end of 1998, Bill's cancer returned. This time it had metastasized to his brain and there were now tumors in his lungs and throat. His beautiful voice — a voice that years before a conference participant had described as a "blend of Carl Sagen and Mister Rodgers" — was in jeopardy. Surgery would be required to

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preserve his speaking voice, and it appeared that his lecturing voice would be gone forever. We were all devastated.

At Christmas, I received a copy of the prayer that Bill had written for his family in a greeting card from Bill and his wife Pam. Overwhelmed by its beauty, I made copies and forwarded it to many friends and colleagues, a gesture that surprised Bill, who often underestimated the power of his words.

Here then are the meditations that Bill wrote in the years following his cancer diagnosis and the prayer he originally wrote for his family. He gave them to us freely as a gift. It is our hope that

they will be circulated widely — to our members and friends and to generations to come — so that we too may learn the kindness of Bill's angel and the freedom of living in the light of death.

This collection is our way of saying how very much we loved this man, how great his contributions have been to our work, and how tremendously we will miss him for all our days to come.

Myra J. Christopher
President and Chief Executive Officer
Midwest Bioethics Center

A World Unraveling

by William G. Bartholome

Although the anxiety and fear that I had carried into the gastroenterology suite in the out-patient radiology department were still very much with me, I found myself feeling quite silly standing there in my underwear and socks with my cute little hospital gown hugging a large metal box and watching the bones of my thorax on the glowing monitor. As I swallowed my chalky barium “milkshake,” I followed the black column of barium as it coursed down my esophagus. “No evidence of obstruction, no dilation,” I reassured myself. However, I did notice that as the barium continued its journey down into my stomach, there was an irregular “bite” missing from the otherwise smooth column. I found myself almost captivated by it as it reappeared with my next swallow.

“There’s a fungating mass in the distal esophagus,” I reported to myself. And, from somewhere inside me came another voice, “You mean in your esophagus.” As I was tying my shoes, the attending radiologist, a woman I did not know, came into the suite with the films (“my films”) in her hand.

“I assume you saw it,” she said, “It doesn’t look good. An irregular mass like that in the distal esophagus is almost always neoplastic. I’m sorry. I’ll give John [my primary care doctor] a call. He’ll probably want to set you up with someone in Gastroenterology for endoscopy and biopsy. May even be able to get it done tomorrow.” I felt the sadness welling up inside me and I nodded, tried to smile and managed to blurt out, “O.K., I’ll touch base with John.”

My nightmare confirmed. Cancer. My “family physician,” John, had laughed at me when I shared my fear with him the Friday before the Upper GI. He had shared with me his own phobia about getting prostate cancer. He was willing to humor me by ordering the Upper GI to document that my problem was nothing more than some irritation of

For reasons I didn't understand, I was not surprised that he was wrong. I seemed to be living out something that had been fated to happen.

my esophagus, reflux esophagitis, the end result of years of dealing with a small hiatal hernia. He felt my minor swallowing difficulties could relate to some degree of stricture. For reasons I didn’t understand, I was not surprised that he was wrong. I seemed to be living out something that had been fated to happen. In some strange way it felt right for me to have a mass in my chest. Seemed like all that was left was for me to experience what was going to happen next, to live it.

When John told the gastroenterologist that he wanted me placed on the GI schedule the next day, the young gastroenterologist, Frank, was more than willing to comply. When he called me to set things up for the endoscopy and biopsy, he apologized for making me wait until the next day! He and his staff in the out-patient endoscopy suite

were more gentle and caring than I had ever imagined possible. I had never experienced such intense caring.

The biopsies revealed “adenocarcinoma of the esophagus in association with a Barrett’s esophagus.” Two days later the CAT scan — done to “rule out any evidence of spread” — revealed a large solitary mass in my liver, presumed to be a metastatic lesion.

I had known Ray, the oncologist whose advice we sought, for over ten years. He was a fellow faculty member, and we shared a background of training and work in the field of bioethics. Pam and I expected his support. He seemed distant, almost hyper-rational. We communicated largely in the arcane language of cancer treatment: survival rates, adjunctive treatments, and Phase II protocols.

[The oncologist] . . . seemed distant, almost hyper-rational. We communicated largely in the arcane language of cancer treatment.

He felt strongly that the only reasonable approach to my disease was surgical. And, if the lesion in my liver turned out to be cancer, the surgery would likely be “palliative” rather than “curative.” His businesslike manner felt cold and brusque. Although he seemed saddened by what was happening to us, he seemed to be unable or unwilling to express those feelings.

He sent us to discuss plans with Jack, a cardiothoracic surgeon, with whom I had “crossed swords” several times in the past over issues related to my role as chairperson of the ethics committee. Pam and I did not expect him to be particularly supportive. We met him in his office late in the afternoon. He was late, but once in the room gave us his undivided attention. He was honest without being brutal. He didn’t welcome, but did not avoid my gaze. He gave us information about surgical

options, but also gave us his recommendations. We selected what he felt was the best chance (albeit slight) for a “curative resection.” He also felt that this same approach was likely to provide the best palliation and that it would “buy us” the most time. On Sunday morning two days later, he called us at home to make sure we were doing O.K. and to inquire once again about any questions or concerns we might have regarding the next day’s surgery. We were both touched by his obvious concern about us as we struggled to prepare for my first surgical experience, what he had called “radical cancer surgery.”

The surgery, the two-day ICU stay, the ventilator, the chest tubes, the N/G tube, the IVs, the PCA pump that refused to work properly, the multiple and recurrent pains of the next twelve days were an ordeal the likes of which I had never experienced. We had only one goal — “recover” from the surgery and get out of that place as fast as we could. The day-to-day experience of being a hospitalized patient only added fuel to our determination to “escape.” I pushed myself to stay at least a day or two ahead of “the recovery schedule” that had been given to us. In order to prove I was ready, I had to show that I could swallow through the reconstructed tube in my chest that had once been my stomach. Chest tube removal was an object lesson in compassion and its absence. The chief resident laughed when I told him I had heard that removing the tubes would be one of the worst aspects of my post-op care. I got no pre-removal morphine from him. The pain was so searing and intense that in spite of myself I cried out for him to stop. Two days later, the intern made sure I got my morphine and we managed to get the tube out by working together: he pulling in one fast, smooth pull; me holding still and screaming. It worked! On my liberation day, it took the intern almost thirty minutes to remove the hundreds of staples in my two “zippers”: one extended the length of my belly and the other wrapped its way around my right chest and back.

The pathology results confirmed our greatest fears. The cancer had found its way through the wall of the esophagus; three of ten regional lymph

nodes contained cancer, and the lesion in my liver was a metastatic lesion. In the jargon of clinical oncology, I was a "Stage IV" patient. There was agreement among my fellow faculty oncologists — no adjunctive treatment was likely to alter my prognosis. Calls were placed to other major cancer centers in the United States. The same response. I was not a candidate for any established oncology treatment. I would be eligible for several different Phase II protocols when my disease was once again "measurable." But no Phase II chemotherapy for my disease had a "response rate" above 20 percent, and none offered a "statistically significant survival advantage over no additional treatment."

My future, our "intended future" (Pam and I had become engaged only six months before this episode), was abruptly "ripped" away, destroyed. My focus became getting all the people that constitute my "web of being" ready for the hole that was to be left by my premature departure. I worked single-mindedly at this "getting ready project" for the next six weeks. I had experienced "grief work" frequently in the past. I had mourned the deaths of scores of patients, close friends, and a marriage. I had taught and written about "death and dying." But I had never experienced this intensity of grief.

I couldn't stop telling Pam and my daughters how sorry I was for having caused them so much sadness and pain; how sorry I was that I wouldn't be there for them in the future. I cried myself dry over and over again, sometimes with Pam, more frequently in the dark by myself. Although sleep brought some relief from this suffering, it also brought recurrent death scene nightmares.

The physical suffering was almost overwhelming: the constant stabbing pain in my chest and back; the search for — and recurrent failure to find — food that would not cause "dumping syndrome"; the need for recurrent trips back to the gastroenterologist for procedures to dilate the stricture that formed and reformed at the opening in my esophagus; and the frightening loss of over thirty pounds in a period of six weeks. I could tell that just being in my presence was a frightening experience for my daughters.

Then without warning came the day of our "rebirth." We had requested a visit with another local oncologist for an in-the-flesh "second opinion." This oncologist had been described to us as an oncologist who worked with hospice patients. Our visit had been delayed several times by difficulties getting the referral arranged through our insurance carrier. We were seven weeks "out from surgery" and I had already had what was

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called my "first post-op CAT scan, the "baseline scan." (Since then, I have not "complied" with the every six months CAT scans that were recommended by our oncologist to "keep track of my disease.") Mike took us into his office. After a few pleasantries and history taking, he took me into an examining room and undertook a systematic examination. He made no attempt to conceal the fact that he was looking for evidence of my cancer. He was more interested in my body's lymph nodes than in my heart. He then took me back to his office to rejoin Pam.

He told us that I was fortunate. My education and long years of experience reviewing oncology research as a member and chair of IRBs in three different medical centers allowed me to "understand" my situation in a way that few cancer patients could. This understanding, he told us, would allow me to do something that few of them are able to do, namely, resist getting involved with oncologists. He pointed out that I already knew that the next step for me was hospice care. Pam grilled him about his analysis of our situation. I was captivated by her power, her willingness to "push" him and his claims about my illness.

Mike then abruptly shifted the focus of our conversation to what I was experiencing. He asked about my diet, my weight, my pain, my mood, my "spirits." He asked about Pam and about us. He even made several recommendations about medications I might want to try to help me better

manage my symptoms, especially the “post-thoracotomy pain syndrome” I was experiencing.

We asked him about the short-term future. We wanted to know if I would likely live for six months since my recently engaged daughter had informed us that she wanted to have her father at her

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wedding. Pam and I also told him we were considering getting married. Mike forcefully stated: “Well, you are clearly not terminal.” I was taken aback and blurted out: “Well, I sure as hell feel terminal.” He disagreed. He noted that my having had a very aggressive surgical procedure (which included the very unusual — in his opinion — feature of a partial hepatectomy) might well have “bought me” considerable time to live before I became a candidate for hospice care.

Mike pointed out to me that I had managed to stabilize my weight; that I had already started back to work; and, that my stricture problem was responding well to the dilation procedures. He gave us both his card as he walked us to the door. As we left we both shook his hand and were surprised by his closing remark: “It was not good to have met you two.” None of us even so much as smiled.

We stopped for a “fancy coffee” on the way home from his office. The sun was shining. I told Pam that I felt that hundreds of pounds had been lifted off my shoulders. I was so relieved that we were to be free of “the system,” free of doctors and clinics and hospitals and the ravages of chemotherapy and radiation therapy. My care, my life was in our hands. Our decisions about diet and exercise and rest would determine the course of my illness. We were free to create whatever life we could build and experience in the time we had left; and we had at least “some time.”

We have lived in the harsh “light of death” since that day. But our life has not been marked by grief or suffering. We have been living . . . living more fully and more “richly” than ever before.

As Helen Keller said almost sixty years ago:

Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure.

Life is either a daring adventure, or nothing. To keep our faces toward change and behave like free spirits in the presence of fate is strength undefeatable.

“A World Unraveling” was presented by the author during a faculty seminar on the “Uses of Auto-pathography in Teaching: A Case Study,” University of Kansas Medical Center, Department of History and Philosophy of Medicine, January 1995.

Living in the Light of Death

by William G. Bartholome

It's been almost a year since I discovered I have a fatal disease. In trying to explain to family and friends what having this period of time has meant to me, I have found it helpful to characterize it as a "gift." It's as though the "Existential Bus" stopped to pick me up back in June 1994, but the bus driver looked out, saw me standing there quaking in my boots, and said, "Okay, okay, Bill, you can stay a while longer, but remember, I'm coming back soon!"

This "Gift" has allowed me to prepare myself, my new spouse (we married in January, six months after learning about my "situation"), and my three daughters for what is to come. It provided me time to revise my Advance Treatment Directives, and to create a Living Trust for my wife and daughters. It has allowed me time to work with my family and to prepare for a future in which I will not be physically present to them. It has given me the opportunity of tying up the "loose ends" that all our lives have. I have been provided the opportunity of reconnecting with those who have taught me, who have shared their lives with me, who have "touched" my life. I have been able to reconnect with those from whom I had become estranged over the years, to apologize for past wrongs, to seek forgiveness for past failings.

But even more than all these, this "gift" has provided me the opportunity of discovering what it is like to "live in the light of death," to live with death "sitting on my shoulder." It has had a powerful effect on me, on my perspective on the world, and on my priorities. I live with a kind of freedom now that I had never allowed myself

before. I am free to be myself, to be what can only be called "radically honest" with myself and with others. On one of our long walks, I told my wife, Pam, that I like the person I am now more than I have ever liked myself before. There is a kind of

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spontaneity and joyfulness in my life that I had rarely known before. I am free of the tyranny of all the things that "need to get done."

I realize now more than ever before that I exist in a "web" of relationships that support and nourish me, that clinging to each other here "against the dark beyond" is what it means to be human. I have experienced a shower of attention, support, and love the likes of which I had never known, including receiving this [Midwest Bioethics] Center's Founders' Award at the MBC Annual Dinner recently. From those who make up my "web of being" — particularly from my new life partner, Pam — I have come to know more about what it means to receive and give love unconditionally.

To live in the bright light of death is to live a life in which colors and sounds and smells are all more intense, in which smiles and laughs are irresistibly infectious, in which touches and hugs are warm and tender almost beyond belief. To live in this awareness of who, what, and where I am is to live

more fully than I ever dreamed possible. Life doesn't seem like a box of chocolates; it seems like endless servings of incredibly rich chocolate mousse.

I had not known this kind of living before. I wish that the "final" chapter in all your stories will be one in which you are given the gift of some time to live with whatever illness proves to be your fatal illness. But even more, I wish that you could

discover what I now know — that this is the only way for us humans to live!

First published as "Living in the Light of Death," *Bulletin* 45(2): 52, University of Kansas Medical Center, April 1995; and in *UPDATE*, Midwest Bioethics Center, June 1995.

STILL/HERE Above Ground

by William G. Bartholome

A little over a year ago I wrote a meditation on “my situation” called “Living in the Light of Death,” in which I shared some experiences and thoughts as a person living in the last chapter of life. I wanted to share the discovery that having this last chapter was a precious gift; that the last chapter in a person’s life could actually be the best chapter. When I wrote it, I never expected to be “above ground” over a year later. It has now been almost three years since I underwent “radical palliative” surgery for my metastatic cancer.

I have no idea why I’m “STILL/HERE” (to borrow the title of Bill Jones’ touring Performance Art show). It continues to be a fascinating and richly rewarding part of my life. However, there are some new challenges involved in my “hanging around.” My wife (and to a lesser extent my daughters) have grown weary of “Living in the Light of Death.” Obviously, for them this means living in the constant shadow of my threatened death. I can’t blame them for wanting to get back to living.

There is a tendency for many who share in my web of being to want me to call an end to the cancer chapter and get on with living. In an important sense, there is no going back. I have been marked by my encounter with death. Having embraced death in the way that I have, I am not the same man I was b.c. (before cancer); in an important sense, I am an Other.

The discoveries I have made over the last two years have powerfully shaped my life, and I have no desire to go back to the frantic life I was living before — a life dominated by things-to-do lists and

organizers and calendars; a life in which I did little more than try to juggle an almost overwhelming burden of things that needed to get done; a life in which the only time I allowed myself not to wear a watch was when I was on all-too-infrequent and too-short vacations; a life in which my needs and

This means not only doing things like “stopping to smell the roses,” but allowing oneself to be radically open to what is going on in the world.

desires were always the last to be considered and the first to be sacrificed.

I am also unwilling to allow my life to revert to the common pattern of living primarily in the future and, to a lesser extent, in the past. I had spent precious little of my life living in the present, in the almost overwhelming intensity and richness of the world around us. This means not only doing things like “stopping to smell the roses,” but allowing oneself to be radically open to what is going on in the world. I find myself stopping over and over again to see or hear or feel something that before my illness would have been lost in the rush of experiences that seems to constitute our lives. I’ve grown increasingly intolerant of living on fast forward, of never having time for what makes life so precious and intensely satisfying: the incredible people who constitute our web of being.

My co-workers have grown weary and somewhat resentful of my willingness to say no, of the degree of freedom I have allowed myself during these months (and now years). Clearly, there is a tension here. My attitude toward work and career has changed significantly. I want to do enough work to justify accepting a pay check and the

I see myself as a person whose "ticket has been punched," as a person who has acquired the disease that will lead to death, a person with a terminal illness.

benefits of my position without a great deal of guilt, yet I find myself with little or no ambition; with no need to prove myself or to advance my career; and no appetite for playing the games associated with our jobs. My being above the fray doesn't always sit well. I also find myself wanting a new challenge, maybe even a new direction for my life, some kind of work that will allow me to share the insights and discoveries I have made about myself and my life over the past two years.

I have also had enough time to clarify my feelings and ideas about my own dying. As a clinical ethicist, I spent much of my career teaching, writing, and assisting providers and health care organizations with the many ethical issues involved in end-of-life care. As a pediatrician, I had discovered the challenges and rewards of caring for dying children and their families. I have been allowed to serve over two hundred dying children in a period of less than thirty years. However, facing my own death has forced me to examine the experience of dying from an intensely personal perspective. I see myself as a person whose "ticket has been punched," as a person who has acquired the disease that will lead to death, a person with a terminal illness. Although I am working full-time and able to do almost anything I was doing before my illness, I am also capable of

seeing myself as a dying person. I have discovered that there are many advantages to wearing the label "dying." I will wear it even more frequently as I develop signs and symptoms of the terminal phase of my disease. A critical advantage of this label is that it will allow me to reap the many advantages of being a hospice patient.

Those of us who work primarily in mainstream health care have been cut off from appreciating the differences between the patient role and that of hospice patient. The paramount values that inform the role of patient are health and longevity. Obviously, beings who were born to age; to gradually decline; to become diseased, debilitated and, ultimately, to die should not have these as the only values that inform their lives. Recently I saw a bumper sticker that spoke to our existential situation in an all-too-real way: "Born to Rot," it read.

The values that inform the role of hospice patient are control and comfort. Providers to such patients assume that they value both being in control of the process of their dying; and, having assistance in dealing with the challenges and burdens of dying, that is, comfort in dying. The shared goal is pursuit of a peaceful death. Care of hospice patients also

Recently I saw a bumper sticker that spoke to our existential situation in an all-too-real way: "Born to Rot," it read.

exposes what I take to be the core, the very heart of what it means to be a healthcare provider, namely, caring. Paul Ramsey has called it only caring to clarify that we must avoid the ever present temptation to attempt to do more; that we must see such patients as needing to be spared the burdens of modern health care's efforts to prevent or cure disease and to prolong life. Cicely Saunders calls it intensive caring to call attention to the fact that this work often involves efforts on the part of providers that are every bit as intensive as those required in intensive care units.

Few mainline healthcare providers have ever experienced this kind of caring for their patients. We get caught up in the practice of twentieth century medicine and nursing; we find ourselves involved in nothing less than battles with diseases that threaten to rob our patients of health; we see our work as being to protect and maximize the health of our patients through the systematic application of the knowledge and technology of modern science. It is no wonder that patients often feel that we don't care. We get so wrapped up in our project that we all too frequently fail to take the time to simply care, no more, no less.

Hospice patients get all the caring they can use. To be cared about and for is the *raison d'être* of the hospice patient. And, to the greatest extent possible, this caring is controlled, shaped, and informed by the needs, values, and goals of the patient, not those of the provider.

So, as I contemplate my death, one issue is very, very clear. I want to be the recipient of the best that modern hospice care can provide. Although I have not had a lot of experience as a patient, I have had

At some point in the not-too-distant future, I will announce to my family and friends that my time is at hand.

enough to know how much I will value the caring that these professionals can provide, and the caring and support that they will be able to provide to my wife, my children, and my family. I know that hospice professionals will recognize, respect, and actively support my plans for my death — the rituals that I have planned, my funeral, and the disposition of my remains.

A major problem facing Americans who are dying is that our society is relatively deficient in what might be called the "rituals of withdrawal" from the world. Much of the clamor for physician-assisted suicide may be fueled by our lack of these

important cultural rituals. Few of us understand that when we are ready to die we can "get dead" without killing ourselves or seeking the help of a health care professional to assist our self-killing. Through study of other cultures and the example of friends who have died, I have become aware of the need we have to develop a wide range of these rituals to support dying people and their families.

Although I am still refining aspects of my ritual, the basic elements are in place. Working with my wife, my daughters, and my family, I have planned my memorial service and the disposition of my remains. We have also made plans for dealing with my responsibilities and for my estate. I have armed my new wife with a durable power of attorney for health care in the event that I lose decisional capacity before I die. We have also had many discussions of my withdrawal plans, particularly as those plans relate to the use or non-use of healthcare interventions.

At some point in the not-too-distant future, I will announce to my family and friends that my time is at hand. Given the size of my family (I am one of twelve siblings) and the good fortune of a number of wonderful friendships, several gatherings will be needed to allow for all to say their good-byes. This withdrawal process is a gradual shrinking of my world; a process of simplification; and a gradual withdrawal from the things of this world. One of the first steps, for example, will be confining myself to home.

Eventually, I plan to retire to a room in our home. Although I will initially watch TV and read newspapers and magazines, eventually I will relinquish this aspect of my world. I will have available the important books that have shaped my life and the photo albums that my daughters and I used to organize the thousands of photos I have taken over the last forty years. Part of my ritual will involve a systematic life-review facilitated by these texts and images. I also plan to allow myself the company of the music that has enriched my life, particularly from the 1950s and 1960s. Eventually, I will need to give up the computer that has enlarged my life and so greatly facilitated all that I have come to call my work.

After a time, I will stop eating, relinquishing chocolate last. I understand that one's interest in food rapidly declines as cancer overtakes organs, particularly the liver. At some point, my world will shrink again from a house, to a room, to a bed. Although I will want the company of my incredible spouse and daughters all the way, eventually our relating will become nonverbal; increasingly, I will seek from them the silent companionship that gives the verb "to company" its core meaning.

Eventually, I will withdraw into myself and my head will become my world. This phase is a critically important part of the process. Because I have frequently spent time in this inner place during meditation, I don't imagine it will be strange to spend more and more of my time there. At the same time that I make this transition, I will withdraw myself from fluids. From the dying patients I have been privileged to serve, I have learned that ice chips can be as satisfying as swallows and won't undermine the strength and resolve needed during this particular phase of the withdrawal process.

Hospice providers have assured me that I will have access to any pharmacological support that I might need for control of a symptom that might impede my withdrawal journey — sedatives if I need help to sleep; hypnotics, when needed, to take the edge off things; anxiolytics to help deal with fears or anxieties; and, most important, any drug needed to control my pain. Since I will be at home, I will likely allow myself use of drugs that are not even listed in the formulary of the local pharmacy.

Having come of age in the 1960s, I have some pharmacological experience regarding alternative substances. Many dying people in the United States have found that smoking at least one of these so-called illicit drugs can ease the burdens of pain and withdrawal. Given the range of drugs and methods of administration available to us,

Americans, particularly those with healthcare insurance, should be some of the least death-fearful people on the globe.

During the final phases of this withdrawal ritual, I will be giving myself over to a process that remains a true mystery to me. Since I didn't call myself into existence some fifty-three years ago, I have no way of knowing what will happen as I leave this world. I have found it helpful and comforting to imagine Death the way my friend and mentor Paul Ramsey talked about it, as the Angel of Death. Although I firmly believe that death entails the end of the self I have come to know over these years, I have no idea what comes next. Although I don't imagine any real continuity of experience, I am open to lots of possibilities; and in no hurry to find out.

Clearly I am blessed to be able to plan this kind of death for myself. Blessed with an incredible, supportive wife; blessed with loving children; blessed with a huge family and a throng of friends; blessed by having a job and health insurance; blessed by having disability insurance should I need it; blessed by having a home; blessed by having access to hospice care; and more.

As a community, we need to support the withdrawal rituals of those who seek assistance in dying. I have seen patients withdraw from the world from many different situations — from beds in nursing homes; from hospitals; even from intensive care units. I hope that we respond to the clamor for physician-assisted suicide by seeing this as an opportunity to bring death and dying into mainstream healthcare; to develop programs necessary to ensure that all dying people can be the recipients of only caring or intensive caring when their time has come.

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Are You Still Terminal?

by William G. Bartholome

September 1997—a little over three years now since my surgery for adenocarcinoma of the esophagus. Since my cancer had already spread to involve multiple lymph nodes in my chest and my liver, we assumed that my surgery was “palliative” at best. Its purpose was to maximize the length of my life and minimize the symptoms I would have to endure before dying, especially those relating to obstruction of my esophagus. After my first year living with my illness, I shared some of my thoughts with the readers of this journal in a short “meditation” entitled, “Living in the Light of Death.” In that text I attempted to share with you my sense of that year as a precious gift. After two years, I wrote a second “meditation” entitled,

“STILL/HERE Above Ground” in which I shared additional thoughts about the value of wearing the label “dying” and provided a brief description of a planned “ritual of withdrawal from the world” for my dying process.

So I hear you asking: what about it, are you still terminal? Regardless of what happens to me in terms of my cancer, I will continue to be “terminal.” Since my oncologists tell me that my lengthy reprieve does not change my prognosis, there is a “reality” that informs my view of my situation. I have been told all along, in no uncertain terms, that it is not a matter of “if” my cancer would take me down, but only a matter of “when.” But I have also discovered that living life as a person with a terminal illness has enriched my life beyond my wildest expectations. I don’t think I can (and have

absolutely no desire to) return to the life I was living pre-cancer, to not be terminal.

I will continue to use, regardless of what happens to me, my adopted “calendar method” of living life. I live each day of the year, each Valentine’s Day, each Fourth of July, each

It has allowed me to do something that I was not doing before my illness, something I think we must all find a way to do — to live with our mortality.

Christmas Day, as if it is the last one of those days that I will be on earth to experience. I am living this fall season with the expectation that I won’t be around to experience another fall. This approach is less impossible, I would argue, than trying to live each and every day as if that day were one’s last day on earth.

But living life in “chunks” of one year has forced me to live in the present. It has enriched my life. It has allowed me to do something that I was not doing before my illness, something I think we must all find a way to do — to live with our mortality. Being terminal is nothing more than being mortal in a shortened time frame.

Living in an age-denying and death-denying culture robs us, cheats us, of the value that only a consciousness of our mortality can bring to our

lives. Few of us seek to maintain relationships with those who have gone before us. Few of us lead lives that are informed by the lives of the dead other than by those of a handful of saints and heroes. Yet death has been called the wellspring of human existence.

My consciousness of my impending death has allowed me to come to an understanding that this wonderful, intense “fleshy phase” of my existence is quite limited. And it has allowed me to discover that what ultimately happens [will be] in the much longer phase of my existence in which I will live on only in the mind and hearts of those whose lives I have been privileged to touch . . . in the lives

of my wonderful wife, our children, family, friends, students, and patients. I want to spend the rest of my days living in the moment — living in the light of death, living as fully and richly as possible regardless of how much time I have left. But I have also come to know how important it is that I live an unforgettable (if not outrageous) life, a life that is so powerfully shaped by joy and caring and loving that I will live on at least until the last days of those who knew me in the flesh.

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May I Be a Cancerous Survivor?

by William G. Bartholome

Every illness has both biological and psychological dimensions. But illness is a profoundly social phenomenon as well. Here I am . . . living in the light of death . . . still/here above ground . . . still “terminal,” but this process . . . this last chapter of my life has now been going on for four years!

Four years ago this June, I underwent “palliative surgery” for what is officially known as Stage IV adenocarcinoma of the esophagus. At the time of my surgery, my cancer had already spread or metastasized. So, obviously I must acknowledge that I am continuing to survive well beyond the time frame of my prognosis. Yet, given the notorious nature of my cancer I am reluctant to embrace anything like the well-accepted social role of “cancer survivor.” I was told in no uncertain terms that it wasn’t a matter of whether my cancer would take me down, it was only a matter of when.

On the other hand, as the readers of this journal know, I have also come to appreciate that having a chance to live with a terminal illness — to live with death on one’s shoulder — is to live a significantly enriched form of existence. I have decided that I want to “live like I am terminal” for the rest of my days regardless of what happens with my cancer.

Which brings us to the strange sounding title of this meditation: “May I be a cancerous survivor?” May I be seen and treated like a person who is very much “with cancer,” and yet, for reasons that are not clear, also surviving? I use the word “may” deliberately. I know I “can” live this way. In fact, living this way is the only way I ever want to live.

In an important sense, I don’t want to have to “give up my cancer.” I don’t want to have “dodged the bullet.” In spite of enormous social pressure, I don’t want to put this cancer episode behind me and go on with my life or — horror of horrors — go back to the life I was living before. Living for these four years with my mortality has so changed my life that for me, now, every aspect of my life is miraculous. As Walt Whitman once wrote: “I know nothing but miracles.”

Take, for example, the incredible explosion of life and beauty we call spring. I don’t want to ever live a fall and winter expecting to see spring. I want to live each day of the calendar of each year of my life as if it will be the last time I am “above ground” to live that day . . . the day of a daughter’s birth . . . our wedding anniversary.

I know now that Death is sugar. Death is what sweetens and enriches life to an extent I never realized. Yet, I know that most members of society do not live this way. Their lives are not illuminated by the light of death. Most Americans live as if they were, for all intents and purposes, immortal. They also live lives that are cut off from the dead, even from family and friends who have preceded them into death. Their systematic denial of death adds to my social isolation and to the isolation of thousands of those who are struggling with chronic illness, life-threatening illness, terminal illness and, especially, from those who are dying.

I am not asking for permission to play the “sick role.” I spend little of my living in the well-recognized social role of “patient” or “cancer

patient." And, given the nature of my illness, I am not willing to wear the label "cancer survivor." So, I find myself asking, will I be allowed to live this highly deviant kind of life? Will those who make up my web of being let me be both part of their lives — as a son, brother, uncle, spouse, father, doctor, teacher, colleague, friend — and, at the same time, cancerous?

Living this long with a terminal illness has also allowed me the opportunity to undertake a sustained and fairly systematic examination of the implications and meaning of my unusual existential situation. For example, reflecting on my situation helped me enormously in understanding the relationship between my situation as a "terminal one," and the reader's situation as a "mortal one." Being "terminal" and being "mortal" are very similar (Did I hear you say: ". . . all too similar . . .?") existential situations!

Dealing with these existential questions has also opened up for me the spiritual dimension of my illness. It has been a spiritual wake-up call. Like many of you, my spiritual experience and reflection is powerfully shaped (both positively and negatively) by the fact that I was raised in a particular religious tradition. So for me, spiritual issues, questions, and challenges are often theological. How do I fit my illness and my struggle to live with it into an understanding of what life is all about . . . into an understanding of myself in relation to God?

Living a life haunted and hounded by death, I seem to have rediscovered a sense of myself as living a life that is haunted and hounded by what the poet Francis Thompson called the "Hound of Heaven." I find myself, once again, struggling with my unbelief.

So, in the course of my spiritual reflection, I often find myself pondering the metaphor: "Death as God." For me, to die seems like experiencing the process by which I came into being — only, in reverse. To die seems to require that I be willing to give myself over to the same power or force by which I came into being in the first place. I didn't,

after all, call myself into being in this particular time and place.

I am beginning to understand that to die is to undertake a profoundly spiritual and, for many of us, theological set of tasks. In the physical realm, to die is to embrace the skeleton that lurks inside me; to embrace the ironic fact that the gift of life contains within it the gift of death; to acknowledge that in some sense, I was born to rot. God is out to get each and every one of us. None of us will be allowed to escape from life without undergoing the decomposition that takes us back to dust.

In the psychological realm, to die is to experience the end of the ego; to allow the process of personal growth and development to come to an end; to allow the light of my embodied consciousness to "go out." In the social realm, to die is to undertake the systematic rending of each strand of the web of being in which I exist.

Each of us was borne in the belly of a woman/mother and nourished at her breasts. Each of us was once a totally dependent infant, literally *enfant*, a "voiceless one." We are, only because we were embraced and nourished and cared for by a community of humans with and through whom we exist.

And, finally, in the spiritual realm, to die is to give one's entire being over to that ultimate source of mystery . . . to enter into the Great Beyond . . . to place oneself in the hands of . . . of . . . ? Don't many of us say, "Into the hands of God?"

In many respects, then, Death and God are cut from the same cloth. Isn't living in the light of death living a life illuminated by an intense Spiritual Light? For me, living with death on my shoulder feels a good deal like what I have always thought it would be like to live with God on one's shoulder. To bend one's ear toward Death is to listen for the voice of God.

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A Prayer

by William G. Bartholome

The “first last Christmas” in 1994 was so bittersweet. I felt in my bones that it would be my last. Yet it was Christmas, that most special time of year. There were many tears, but much joy. Little did I know that this was just the beginning of an incredible journey. A few weeks later, a force . . . an incredible grace . . . entered my life that would nourish and transform me in ways that I had never known. Although I barely knew it, our wedding was an awesome creation of life in the face of my illness. Pam tied her life together with mine in a way that has nourished me and grown me as a human beyond my wildest imaginings:

*Thank you, God, for my partner,
my wife, my Pam.*

Over the course of these last four and a half years, I have become profoundly aware of the nature of my existence as a human being. I have come to realize that I exist suspended in, defined by, and nourished through a web of relationships. I know that I am because a man and woman conceived me into existence; because a woman bore me, birthed me, nourished me, cared for me and protected me. From a wonderful mob of siblings, I learned the lessons of sharing and loyalty and solidarity. From a long and troubled marriage and the searing pain of a divorce, I came to know that a needful love cannot maintain a relationship; that each of us is also called to sustain a solitary self.

From three incredible daughters and now a son, I have learned of the work, the joy, the pains, the satisfactions, the failings, and the letting go of being

a father. From friends, from students, and from my patients and their families, I have learned the meaning of living-in-relationship:

*Thank you, God, for my parents, my siblings,
my children, my web of being.*

During this special time, I have been blessed in ways that I had never imagined possible. I have come to an awareness of myself and my life that few human beings are ever afforded the opportunity of developing. By making the choice to live in the light of death, I opened myself up to a process of discovery that continues to this very day. I am open to the beauty and intensity and richness and goodness of the world around me in ways that I had never experienced. I continue to be stunned and overwhelmed over and over again with this kind of living. I have come to know what it is like to actually live in the present . . . to be totally alive in a moment of time:

*Thank you, God, for this opportunity to be truly
alive.*

I have also been allowed to come to the discovery that this precious gift we call life is ours to make of what we will. This above ground, “fleshy phase” of our existence is a precious opportunity we are given to experience this world, to build bonds of caring and love with each other, to come to know what we are called to do here, and to create a legacy that will endure.

Over the last four years, I have attempted to share with all of you — but particularly with our children — my love, my spirit, my mind/heart. In

the meditations I have shared with you, I have given you the gifts of my discoveries. I want more than anything to be for you a "way-shower," a guide, a teacher:

Thank you, God, for this opportunity to guide.

Living in this process has also grounded me in the awesome reality of Death. I have come to know the skeleton I am in the process of becoming in ways I never imagined possible. I feel His presence in my body in my every waking moment. Yet, I am no longer terrified by this reality. I have come to understand that it is Death that is the wellspring that drives our lives. Without Death, our lives would be pointless and empty. It is Death that wakes us to living. It is Death that prods us to discover and create ourselves and our lives in the few precious years we are given to share with each other here with our Mother Earth. I have encouraged you to embrace this strange travelling companion. His presence in your life will enrich your journey:

*Thank you, God, for giving us this gift of life/
death.*

This journey has also opened up in me a renewed awareness of the relationship between my being and Father Sun and the Cosmos beyond. As I told you, living with Death on my shoulder has opened up in me an awareness of God's haunting presence. I know that God is. For me, beyond this awesome presence there is nothing but dense mystery. Yet, this one step of faith . . . this simple conviction transforms me and my life.

At St. Andrew's Church, I now go to communion. I go to "feed on Him in my heart through faith." I am once again being spiritually nourished. Our service ends with the saints gathering around the altar and reciting an affirmation of purpose:

Go forth into the world in peace, be of good courage, hold fast to that which is good, render to no one evil for evil, strengthen the fainthearted, support the weak, help the afflicted, honor all people, love and serve the Lord rejoicing in the power of the Holy Spirit:

Thank you, God, for bringing me back to your presence.

I have been so blessed. You cannot possibly know the depth of my gratitude at having had these precious years to share with you. This special time of Christmas calls for celebration, joy, and acknowledgment of the multitude of gifts that fill our lives. This whole journey has been for me an incredible gift. I have had the opportunity to experience life and love and joy and peace beyond my wildest dreams:

Thank you, God, for this great gift.

Presented at a family prayer service and distributed privately, Christmas 1998.

Lessons from the Angel of Death

by William G. Bartholome

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.

*And if people ask me
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it was getting married,
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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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