
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

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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

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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

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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

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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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