
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!

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