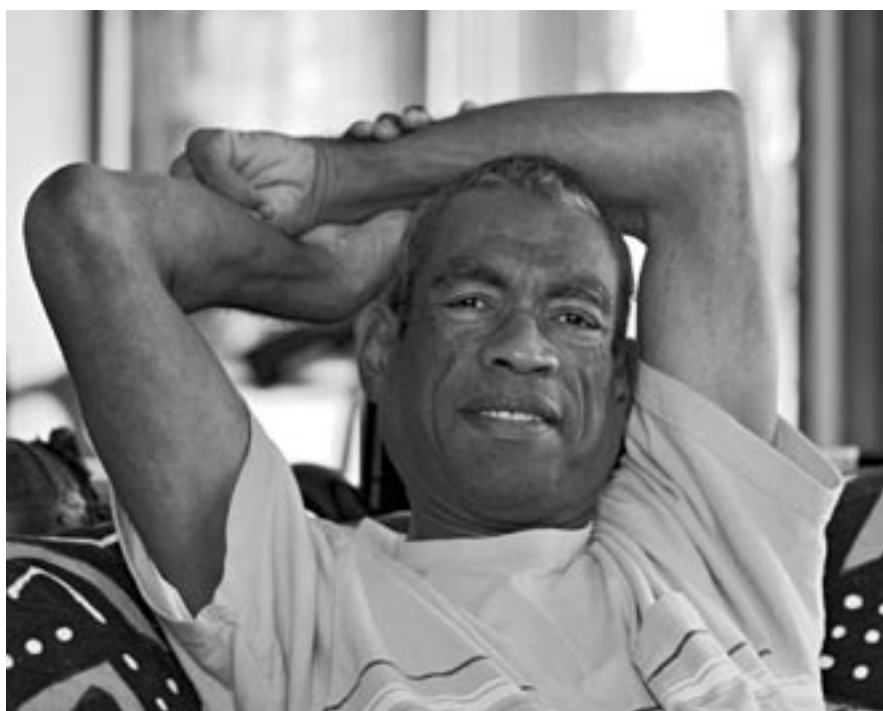


## Finding the Light in the Strangest of Places

by Curtis Grindahl



Will Carter's T-cell count is zero. After nearly twenty years battling a virus Will refers to as "him," the complex regimen of drugs that kept this unrelenting invader at bay no longer works. When I first met Will he showed me a photograph of what appeared to be a robust young man, then reported that his friend had died only six weeks after the photo was taken. Clearly, he wanted me to understand that he is ever at risk for a sudden and possibly fatal decline in health.

In the last year, Will has had two bouts of MAC, Mycobacterium Avium Complex, a serious bacterial infection afflicting those who are HIV+ and whose T-cell count drops below 50. The symptoms of this opportunistic disease can include weight loss, fevers, chills, night sweats, swollen glands, abdominal pains, diarrhea and overall weakness. MAC usually affects the intestines and inner organs first. Swelling and inflammation also occur. The first episode put Will in the hospital for an extended stay.

He came to San Francisco in the early 1980's, which put him at the front lines when this disease appeared. By the middle of the decade he found himself infected with HIV and soon became a member of one of the early support groups.

Will was a member of the Westside Community Health group, which included 15 to 25 participants. As members died or moved on, new members would join. To the best of his knowledge, Will is the last person

*The Living/Dying Project offers spiritual support to those with life-threatening illnesses. Spiritual support can include meditation instruction, talking about death and associated fears, being quiet together, telling the difficult truth, just listening with compassion for other and for self, eating chocolate ice cream together, or being fully present at the bedside of someone whose heart and brain are ceasing to function.*

*The easiest stories to tell about spiritual support are the ones that*

*are dramatic, include a sudden transformation, have a satisfying ending. Will Carter's story has none of these; it is gradual and unfinished. Will's path has become his goal. Struggle and surrender are becoming one. The undramatic precariously balanced between life and death.*

*Will shares with Project volunteer Curtis Grindahl his changing relationship with the AIDS virus in his body, his life lived on the edge, and his feelings about his death.*

— Dale Borglum



*I see no impurities.*

—Maharaj-ji

from the support group still alive. Today he is a member of another support group whose participants are all long-term survivors sharing the challenges of this journey. When Will broached the subject of dying with members of the group, not simply as the end of life but as part of a process of living, he was met with responses that suggested the subject was simply too disturbing to examine closely. It was then that he called the Living/Dying Project.

Will expressed the intention of exploring dying within the context of living, and living within the context of dying. As his condition deteriorated he found himself crossing a line he hadn't noticed during the many years he offered solace and support to friends, their families and loved ones ravaged by AIDS: He no longer has the physical and emotional stamina to take the lead in solving people's problems on a journey that often leads to death.

When I broached the subject of writing something about his journey, Will offered to record our Living/Dying Project one-to-one sessions. He remains committed to dealing with health problems as they arise but is always mindful of his vulnerability. During the weeks we've met, Will has been scanned and poked repeatedly as doctors attempt to make sense of the latest assortment of symptoms.



I'm stumbling . . . There's a path here but I don't know exactly where it goes. There's so much to this life that I don't know how to do . . . There's a lack of perspective . . . We stumble through it. There is a constant tension, a polarity between the forces trying to expand, coming into something new as other forces cause me to contract .

I'm trying to incorporate meditation into my life . . . It occurs to me that the meditative state and the death state have a lot more in common with each other than my normal day-to-day state does with either one. At this point I'm finding a peacefulness I haven't felt before.

Things change, but I try to keep myself at the point where this peace continues. Then stuff like MAC comes up, like a Jungian metaphor. Stuff pops out of the ocean, I don't see it coming. All of a sudden here's this sea monster. The first thing I see is how big it is in comparison to the little boat I'm in. *It happens* to me. . . My doctor doesn't call and say in three months I'm going to get MAC. . . I only know I've got it when I get it; it just appears. I can worry about "X", but I don't know what "X" is . . .

I've spent a long time chasing this disease, active with people exploring AIDS politically, psychologically and medically. No one wants to think about this stuff: the shots, the medication . . . I've spent most of my life on drugs, going to doctors, feeling miserable . . . There are these little deaths: an episode of diarrhea is a little death . . . so many of them in life. The question for me is how to get more life out of living, less death out of living.

Trying to meditate the other night, I couldn't catch my breath . . . trouble breathing at night, it becomes erratic. I was remembering a guru who said, "Think your breath is unimportant? Wait until you get to the point where you're trying to catch it." The breath, where is it? It just sort of happens, it's a little death to me . . .

Before you begin to pray,  
decide that you are ready to die  
in that very prayer.

There are some people so  
intense in their worship,  
who give up so much of  
their strength to prayer,  
that if not for a miracle they would die  
after uttering only two or three words.  
It is only through God's great kindness  
that such people live,  
that their soul does not leave them  
as they are joined to God in prayer.

—Zawa'at RIVaSH, Hasidic Text

The first person I saw in death who changed my perspective was my foster mother, Isabel, seeing her in that casket. This was so far away from anything that she was. No spirit there, no life . . . This might have been one of her old dresses . . . I understand the importance of rituals of death, but I saw no life there, nothing left of her, not her body . . . It was a great learning for me. I've used that memory often.



*Your greatest weakness is but a warping  
of your greatest strength.*

—Sufi Aphorism

I experienced that with other friends. Many of the people with AIDS had twisted deaths, the body left after the battle of life and death . . . twisted in many ways, emaciated, grotesque from death, from the dying. Weeks and months of battle. The husk was all that remained of these great, beautiful beings.

I wanted to talk about this with folks from the Living/Dying Project because the message I've been getting was I shouldn't talk about this. It bothers me. I thought I was being proactive, but my group's response was they didn't want to talk about it. Death is taboo. Coffins from war are not to be seen. We alter reality. These kids are coming back dead, in flag draped coffins . . . When we say yes, we say yes to that too.

It was a given from the beginning that the virus and I were in a battle and that he would win. The context of winning has shifted . . . It took twenty years to kill me. I have smiled because I know this virus so well. It's personal. "He" took my life, "he" took the fun, "he" took the lives of my friends. Everybody has learned at this point in my life not to say anything nice about the virus around me . . . This has been a struggle, a battle, a life-consuming effort. If I could go at "him" one more time . . . I battled "him" . . . It would be one more battle, from the grave, one last time.

People live as though they'll live forever, anticipating what they'll be doing in five years. I can't do that. Three to five years from now, who knows . . . I don't have the mechanism to lay out a plan, to put all the pieces on the chess board. My plans are very simple. Planning is futile, a waste of time. It would take me away from finding who I am in order to create a chimera of who I want to be. Life then becomes very simple. I'm surprised that this is okay just as it is.



*In this world  
we stroll along the roof of hell  
gawking at flowers.*

—Issa

I don't try to find solutions to the world's problems . . . so much we get lost in, looks like it's meaningful . . . and yet it is so NOT.

*to page 5*

# HEALING AT THE EDGE

A WORKSHOP FOR THERAPISTS AND CAREGIVERS  
OPEN TO THE PUBLIC



For over twenty years, I have been blessed to be in close contact with many people who were approaching death. Almost all of these people were reaching out for healing – healing in relationship to death, healing in relationship to illness, in relationship to a wounded heart, to separation from their own self. My consuming interest, both personally and professionally, has been the healing process. Why do some people as they approach death experience a profound sense of wholeness, while others lose themselves in denial, depression, distraction? Why is it that the most alive and awake Westerners I've known have been, almost without exception, people near death? Is there some powerful truth about life and about healing that you and I can receive from those few who, as they went through the process of dying, deeply realized their own wholeness?

*Dale Borglum*

THIS WORKSHOP WILL EXPLORE POSSIBILITIES FOR REALIZING WHOLENESS AT THE EDGE OF LIFE WHERE ILLNESS, GRIEF, LOSS, ADDICTION, AND SPIRITUAL YEARNING ARISE. BOTH PSYCHOLOGICAL AND SPIRITUAL TOOLS WILL BE USED IN THE INVESTIGATION OF THESE PROFOUND AND OFTEN DIFFICULT ISSUES. WE WILL OFFER PARTICIPANTS THE OPPORTUNITY TO EXPLORE THE DEEPER QUESTIONS SURROUNDING DEATH, HEALING, AND THE SACRED SO THAT WE CAN BETTER EMBODY AN ENLIVENED SENSE OF BEING IN THE WORLD IN EACH MOMENT RATHER THAN A SENSE OF ISOLATION AND DENIAL.

EXPERIENTIAL EXERCISES WILL BE PART OF THIS WORKSHOP  
WITH EMPHASIS ON THIS KIND OF WORK IN DAY TWO.

There are two training groups available:

MARIN	EAST BAY
SATURDAY, FEBRUARY 25, 2006 10:00 A.M.–5:00 P.M. SUNDAY, FEBRUARY 26, 2006 10:00 A.M.–5:00 P.M.	SATURDAY, JANUARY 28, 2006 9:00 A.M.–5:00 P.M.
SAN FRANCISCO THEOLOGICAL SEMINARY GENEVA HALL 105 SEMINARY ROAD SAN ANSELMO, CA 94960	ST. JOHN'S PRESBYTERIAN CHURCH 2727 COLLEGE AVENUE BERKELEY, CA 94705-1247
<b>12 HOURS C.E.U. \$180</b>	<b>7 HOURS C.E.U. \$120</b>
<p><b>PRE-REGISTRATION IS ENCOURAGED. SPACE IS LIMITED. \$20 EXTRA FOR REGISTRATION AT THE DOOR.</b> CHECKS SHOULD BE MADE PAYABLE TO: LIVING/DYING PROJECT AND SENT TO P.O. BOX 357, FAIRFAX, CA 94978 Refunds will be made only with notice given at least two days in advance of the workshop by calling 415-456-3915 or by e-mail addressed to <a href="mailto:info@livingdyingproject.org">info@livingdyingproject.org</a>.</p>	



Workshops will be conducted by Dale Borglum, Ph.D. With Stephen Levine and Ram Dass, Dale established the Hanuman Foundation Dying Center in Santa Fe, New Mexico, the first center supporting conscious dying in the U.S. Dale directed the center until moving to the San Francisco Bay Area. He is the founder and Executive Director of the Living/Dying Project and co-author of *Journey of Awakening: A Meditator's Guidebook*, Bantam Books. He will be assisted by Curtis Grindahl, M.F.T., who serves as Intake Coordinator for the Project.

Board of Behavioral Sciences Provider Approval Number 3849. Board of Registered Nursing Provider Number 9621. Courses meet the qualifications for 7 and 12 hours of continuing credit for MFCCs and/or LCSWs as required by the CA Board of Behavioral Sciences. Refunds will be made only with notice given two days in advance of the workshop by calling or e-mailing the Living/Dying Project. A \$15 processing fee will be deducted from refunds issued.



## Between

Perched in a window sill  
I listen to fluid fill father's lungs.  
His face and hair opaque white.  
Skin over bone drawn tight,  
his nose like a bird's beak.

I flew a redeye across.  
Left my daughter  
graduating among  
budding sycamores.  
She strode to accept her diploma  
through a threshold of applause.  
Both of them—commencing.  
Between my father and daughter  
my arms stretch wide. In father's  
death I lose myself as son.

Now I breathe with him.  
Long pause  
before the next inhale—  
testing our trust  
that another breath will be there.  
Across the courtyard, the brick wing  
where I was born. Violent entry  
leaving my arm limp in a sling.  
The doctor told mother not to worry:  
He will fight the next war.

Tears fill my eyes.  
His death buffered only by  
my brother's shared grief,  
my children beginning to bud,  
and the stark aliveness that rings  
beginnings and endings.

—Sandy Scull

Strange to me: when the big guy comes, it will be as it will be and there's nothing anyone can do about it. In this life, we know there is something out there, but we're not going to deal with it as though it's a reality . . . We simply don't pay attention.

When I die all this goes, the meat and the matter of this goes . . . Once I'm gone, this means nothing. You can put it in a couple of bags and put it out for recycling . . . One thing I was thinking about, a little macabre: willing my body to UCSF.

I'm doing what I can do . . . I feel well balanced in this precarious perch between life and death. It can happen, death can come along at any point. The most important thing about this body is NOW that I have it. My thing is to enjoy, try to find meaning in what I have left. I'll only have it left this once in my life . . . An old line from the Grateful Dead comes to mind. "Once in a while you can find the light in the strangest of places if you just look at it right." That's how I want to look at this.



Recently, Will began a new regimen of medicines to see if his immune system can be reactivated. The medicines have side effects, including hiccups, that have been with him for over a month. A CAT scan, administered to see if there is a tear in his esophagus, revealed anomalies that led to further tests, including a colonoscopy, endoscopy, additional scans and a bone marrow biopsy. The challenge facing Will is finding life in the midst of these medical interventions. We are continuing our conversation about this remarkable journey: living in the face of dying.

As this article was nearing completion, Will entered the hospital for further tests. He informed me by e-mail, "Unfortunately, my health has taken a turn for the worst." Will's prognosis is unclear at the moment and I've been unable to review the completed article with him. Since we had many conversations about telling his story based upon his recordings, I have confidence that he would wish me to publish this article in the Living/Dying Project newsletter. I'll share it with him the next time we meet.

## Mission Statement

Imagine facing death without fear.

Imagine using a life-threatening illness as an opportunity for spiritual awakening.

Imagine approaching the unknown with an open heart.

We often resist change as a natural part of life.

Strength and healing can be found in life's most difficult situations.

The Living/Dying Project offers compassionate support in the spirit of mutual exploration to those facing life-threatening illness.



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## The Living/Dying Project

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## Supporting Us

The Living/Dying Project continues to offer free-of-charge spiritual support to those with life-threatening illnesses in the San Francisco Bay Area as well as educational services both locally and beyond Northern California. The mission of our work is the healing of our collective and individual relationships with death and hence with our lives. Now as always, it is vital to keep that which is most meaningful and inspiring to us at the motivating center of our actions.

Our operation is simple; our budget is basic; our overhead is minimal. We ask for your support, both financially and your kindhearted wishes and prayers. In addition to donating via the enclosed envelope, there are three more ways to support us financially:

- ☞ We are now a member of the escrip program. To use this service, go to [www.escrip.com](http://www.escrip.com) and register, after which 2%–6% of purchases you make at Whole Foods, Macy's, Andronico's, Good Earth and dozens of other stores will automatically be donated to the Project. To register with escrip, please use our group ID#500002940 or the name Living-Dying Project (rather than Living/Dying Project with a slash).
- ☞ Shop at Under One Roof, a gift store at 549 Castro Street in San Francisco.
- ☞ Visit [www.underoneroof.org](http://www.underoneroof.org), which offers home décor and personal items. All of the profits go directly to 35 agencies (including us) in the Bay Area that support people with AIDS.

We received many gifts and donations last year. Our heartfelt thanks to each one of you. May this holiday season and the year to come be filled with happiness and blessing for you and for those you love.

Dale Borglum, *Executive Director*

## Credits

Desert Wash at Sunset on page 3 and Coulter Pine Cones on this page were shot by George Ward, an old friend of Dale's and a good friend of the Project. A professional photographer, George's work can be seen at [GeorgeWard.com](http://GeorgeWard.com).

The photographs of Will Carter on page 1 and Canal Ripples on page 5 were made by Curtis Grindahl, a Living/Dying Project volunteer. For more photos by Curtis, go to [trekearth.com](http://trekearth.com).

Heartfelt thanks to Steven Englander of Interface Design (415 388-7744) who once again beautifully designed and copy edited this newsletter.

Sandy Scull, who wrote the poem "Between" on page 3, and Steven Englander, are also Living/Dying Project volunteers. It has been a joy and a privilege to be free with Curtis, Steven and Sandy over the years that they have selflessly offered their time and talents to the Project.

