

## Constancy and Change

Since our last newsletter, what has remained constant with the Living/Dying Project is our commitment to serving individual clients. In this issue, the poem Facing the Wall and the articles Reflections of a Volunteer and Approaching the Unspeakable speak directly to our commitment to bring spiritual support to those with life-threatening illnesses.

The Living/Dying Project was the first organization in the United States whose mission was to offer conscious, spiritual support to those with critical illnesses. Even today, over thirty years since our inception, there are only a handful of organizations whose main mission is to offer such support. Such is the depth of the denial of death in Western society.

I deeply feel it is of utmost importance that

we continue to offer our living model of nondenominational spiritual support, support in language and tone available to anyone reaching out for this support, not just those who meditate or study Eastern religions or New Age thought.

As we can clearly see, our political and financial systems and the environment – all are out of balance as a result

of misplaced priorities. It is crucial that we as a society pursue collective healing that addresses as directly as possible the root cause of these imbalances. If we truly know deep in our bellies that we are going to die but we don't know when, if we truly know how precious life is, can we then still act in ways that are based in

greed rather than compassion?

Our individual and collective denial of death and our fear of death is the root cause of our collective inability to act with compassion.

During the past year there has been a significant increase in our educational outreach. As you may remember from previous newsletter articles, I experienced a personal financial crisis two years ago. Before this crisis, what I had learned in a lifetime of seeking Truth was valid, yet only after being pushed to the edge of the







abyss was I forced to put into moment-to-moment practice the wisdom I had been blessed with, from intensive practice of meditation, from many years at the bedsides of those who were dying, and from the psychological and bodily-based disciplines I had explored.

My fear of annihilation was gradually transformed, sometimes painfully and sometimes gracefully, as I surrendered into that Presence that is the Ground of Being in each of us. This process is not complete, but I have been compelled to confront the emotional and energetic blocks to this surrender. Many times I have wished that there were an alternative, but gratefully there was none. Left with no choice, I was driven to find a healing model that worked, even for my neurotic mind. Along with this happy discovery came the inspiration to share it with anyone wishing to heal, to awaken – whether they feel they are living or are dying.

The ongoing small groups that I facilitate, called Healing at the Edge, have brought support and transformation to many of the group members. Leading these groups has inspired me to use my mind to make more accessible and workable my model for the path to wholeness and to use my heart to love more consistently each group member.

Maharaji said, “Love is the best medicine” while the Dalai Lama, on his third visit to the U.S., said “I am just beginning to understand, Americans don’t like themselves.” How can someone who doesn’t like her or himself dis-identify with ego structure and dissolve into this best medicine, love?

Most contemplative traditions were developed 1,500–3,000 years ago by and for people who liked themselves and their parents, were grounded on this earth, were centered in their bodies and were basically un-neurotic. How many people like that do you know? How likely are confusion, stagnation or blockage when someone who doesn’t fundamentally like her or

himself attempts to dis-identify from ego structure and surrender into the spaciousness of Presence, of Love?

In these groups, we create a stable foundation from which to embrace with mercy and compassion that which blocks the free expression of our hearts and, from there, to rest in our True Nature. We explore together the developmental stages of the path to wholeness. We begin with:

Motivation – We ask the questions, *How alive are you willing to be? What really is the primary goal in your life?* The resulting motivation inspires...

Invocation – From the depth of the yearning in your heart, invoke that which you trust. From your body, invoke that which it trusts, groundedness, resting on this earth. Then become centered in your belly, firm as a mountain, so when the sky-like heart of compassion opens, supported by a full belly, the open heart is stable, unaffected by each passing emotion.

Compassion – The spacious and selfless heart of compassion supports the opening of the wisdom mind that sees all as an expression of the One. This is just the first part of our conceptual framework that supports the practices that we explore together, though the true gift of these groups is the vulnerability, love and caring that has grown for all of us over the months.

Is there a joy that transcends happiness and sadness, wellness and illness, even life and death? Hope to meet you there!

—Dale Borglum, *Executive Director*

## New Features at Our Website

The Living/Dying Project received a generous grant from the Lloyd Symington Foundation that brought us halfway to our goal of having the go-to website for people with life-threatening illnesses who are pursuing deep healing and seeking spiritual support. The site, [www.livingdying.org](http://www.livingdying.org), has been expanded with much new material. We invite you to have a look:

### Audio

The site now includes transcripts of guided meditations by Stephen Levine – not available anywhere else on the Internet; audio files by me of guided meditations at my Healing at the Edge groups; a recording of my talk at the Berkeley Chaplaincy Institute; a discussion between author Anne Lamott and myself; and several transcripts of wonderful meditative practices by author Joan Halifax, the abbot of the Upaya Zen Center in Santa Fe and founder of the Ojai Foundation. Stephen has also agreed to post some of his new poetry at our site.

### Healing at the Edge groups facilitated by Dale

A description of the Healing at the Edge small, ongoing groups is at the Events and Groups link. Currently there are groups in Berkeley, Sebastopol and Fairfax. For those who do not live in the Bay Area, Skype or telephone counseling is now available.

### Forums

We have launched forums that will create supportive online communities for those engaged in caregiving, healing, working with life-threatening illness, or for general discussion.

### From our beginnings – The Dying Center

Another new section describes the Dying Center in Santa Fe that, as part of the Project, was the first residential center dedicated to dying consciously in the U.S.

### Going green

You can now join our digital mailing list and choose not to receive a print version of the newsletter. The Project will save money on printing and postage, as well reduce paper consumption. Please avail yourself of this option if you don’t actually need a physical copy of our newsletter.

*Like the Mother of the world who carries the pain of the world in her heart, each one of us is part of her heart and therefore each one of us is endowed with a certain measure of cosmic pain.*

*You are sharing in that pain and are called upon to meet it in joy rather than self-pity. The secret, offer your heart as a vehicle to transform cosmic suffering into joy.*

—Pir Vilayat Khan

Labyrinth on Loma Alta Ridge  
by Dale Borglum



*Do not look for rest in in any pleasure, because you were not created for pleasure: you were created for Joy.*

*And if you do not know the difference between pleasure and Joy you have not yet begun to live.*

—Thomas Merton

# Approaching the Unspeakable



Melissa Spivack by Curtis Grindahl

This spring, I went to do the intake interview with Melissa Spivack, a 47-year-old woman who is almost four years into her journey with ALS, amyotrophic lateral sclerosis, best known as Lou Gehrig's disease.

Her caregiver, David, led me to the brightly lit bedroom at the rear of the home. A rail had been installed in the hall ceiling, running from the bedroom to a nearby bathroom. I glanced inside as we passed and saw the rail terminated above the toilet. Clearly, great attention had been given to anticipating Melissa's needs as this disease progresses.

Melissa was comfortably settled on a wide hospital bed, working at her computer. She was controlling the computer cursor by means of a device attached to her eyeglass frames, selecting each letter and/or word that appeared on the screen as she slowly expressed herself.

Before diagnosis with ALS, Melissa worked in business and occasionally traveled internationally. When the definitive diagnosis was given, she went into action. She hired David and arranged for retrofitting of her home. While contractors installed an elevator, created an apartment for David, outfitted the bathroom with a shower chair and special toilet and installed the railing in the ceiling, she and David traveled to the Boston area and stayed with her family for three months. Upon returning, her San Francisco home was ready for the next stage of her journey.

Melissa's support system is extensive, including family, friends and professionals. David transports her with a specially outfitted van that accommodates her powered wheelchair. We also discussed the support she hoped to receive through the Living/Dying Project.

Lyn Davis Genelli, a Project volunteer, was matched with Melissa. What follows are Lyn's reflections on her work with Melissa over the past months:

*Melissa is lying motionless in a hospital bed. Her life-experience is wide-ranging, her intelligence immediately impressive. Her writing style on the computer is precise and even slightly formal as she seeks out, then "types," each letter. She talks about her daily struggles and decisions like the feeding tube. She has just begun to talk about death but moves away from the subject quickly. She knows she has a ways to go yet. Despite her enormous limitations, she remains in command of her world, with the exquisite help of her nursing assistant, David.*

*This is a house filled with love, especially the profound intimacy shared by Melissa and David, who regard each other as the love of their lives, and speak of each other as spouses. They share a kind of telepathic bond, which allows David to sense her needs intuitively despite her inability to speak. David cares for Melissa with deep devotion and she has opened her heart to him fully. In the midst of this catastrophic illness, there is unexpected love. Each day they live simply together, performing the endless rituals of Melissa's bodily care. Each day they laugh together.*

*Melissa is still engaged with her community and family. Recently, Curtis and I attended Melissa's 47th birthday party, where the photo to the left was taken. Melissa, in her huge wheelchair, looked like a queen on her throne, receiving her subjects. The house was filled with friends and family, all of whom spend time with her regularly, as well as communicating by email. They were grateful for what the Living/Dying Project is offering, how our presence on the scene allows them to feel more at ease about Melissa's inner well-being.*

*The body passes away. Everything is impermanent except love of God.*

—Maharaji

*Dying is a profound inner journey, taken entirely alone, and yet being with Melissa is also a family journey. I've met Melissa's mother and tasted her superb apple pie, and spent a long time talking with Melissa, her father and her stepmother, Marilyn. They long to talk about their feelings and worries with Melissa, and having a volunteer present helps to facilitate that.*

*David is determined to sustain Melissa's life and has the conviction that he can do this by the power of his love. Even in the midst of death, he keeps them both turned toward life through this love.*

Recently, I visited Melissa to discuss the article. Here is what she had to say:

*I made a decision to tell people my news soon after diagnosis. I wrote to groups who knew me from a common context. My goal was to make the unspeakable approachable.*

*I had zero understanding of ALS. I read all the information and it felt like something that was happening to me even as it was. It's not that I was in denial. I kept adapting. But I still didn't know what it would feel like to be so completely dependent.*

*I believe that because of my relationship with David, not only have I lived longer, but he keeps me engaged. He's also incredibly annoying at times!*

*The hard part is clearly in front of me. There are times when I am deeply depressed. I am on a lot of antidepressants. I want to feel like I want to get up in the morning, but I want to feel the process too.*

*You and Lyn have been amazing. I am beginning to feel I have a safe place, without everyone else's agendas, to talk about choosing death. I said earlier that I didn't understand what ALS meant for living. I have always known I would have to choose how and when I die.*

Melissa noted how her outlook on life changed for the better during her journey with ALS and that fact was bewildering for her friends. Yet those close enough to observe how her heart has opened surely recognize the gift that has come to her. Melissa expressed her fears, in part about where this is going for her, but also her concern for David, whom she will be leaving. As always, my approach is to support and encourage the person to remain open to what arises moment-to-moment along the journey.

Certainly no one would wish upon themselves or someone whom they love a journey as harrowing as that taken by those with ALS. But if one must take this journey, it is grace when one is able to open one's heart along the way. Melissa shows us it is possible to do.

—Curtis Grindahl,  
Client Intake Coordinator

*The only mistake in prayer is to pray as if God were not present.*

—St Theresa of Avila

El Capitan Seen Through Forest Clearing by George Ward





# Reflections of a Volunteer



Curtis Grindahl

In Buddhist teaching, the story is told of a mother grieving the death of her only son. She takes his body to the Buddha to find a cure. The Buddha asks her to bring a handful of mustard seeds from a family which has never lost a child, husband, parent or friend. When the mother is unable to find such a house in her village, she realizes that death is common to all and she cannot be selfish in her grief.

Before beginning my clinical internship as a marriage and family therapist twenty years ago, I volunteered at an agency that offered grief counseling. My first job was to read death certificates from the county coroner's office, to identify the family member who would be contacted with the offer of free counseling

Each week I'd read through a stack of certificates. Although by that time I'd experienced the death of grandparents, one parent, a teenage friend killed by a hit-and-run driver as I stood nearby, and two co-workers in their thirties, it wasn't until I held the pile of death certificates that I fully understood what this mother discovered in the tale of Buddha. I not only read the names of survivors, but also everything written about the deceased person's disease and life. These were real people with real families and their lives had come to an end, whether quickly or slowly.

Twelve years ago, I came to the Living/Dying Project to be of service and to come to terms with my own mortality. In his training workshops and volunteer support group meetings, Dale Borglum makes clear that although the service we offer to people approaching the end of their lives is honorable and valuable, it is our own personal transformation that is at the heart of the work. The question eternally being asked is, "How do we contract when confronted with suffering, with the unknown represented by the end of life?"

I've written about my relationship with Will Carter, the longtime survivor of AIDS, and with Denlow, whose journey with Lou Gehrig's disease inspired so many. But I haven't written about the 33-year-old woman who died within six months of her diagnosis from a disease that mysteriously appeared shortly after her marriage; or about the woman who suffered for much of her life from what was then called Multiple Personality Disorder, and who'd lived on the street for years before pulling her life together and taking a job as a social worker; or about the man whose son was killed in Columbia by FARC rebels, who had so much anguish over that loss he was unprepared for his own passing; or the man whose home overlooked the Pacific Ocean, with whom I met each week and gazed toward the horizon, contemplating life's complexities while saying farewell.

As Intake Coordinator for the Project, I meet with prospective clients, both to learn about their disease and to determine what they are seeking in the way of support, before a decision is made as to which volunteer will work with each person.

Most recently I met with a woman in her forties whose cancer appeared four years ago when her daughter was born. Despite remission and three years of relative health, the cancer returned. This woman died last summer, leaving behind her husband and two children. The poem Facing the Wall on the next page was written by one of our volunteers, Sandy Scull, about his work with her.

Reflecting back on these years, I'm aware of the gifts I've received as a volunteer. In my last article about Denlow's passing, I wrote that my heart had been broken during my two years with him. But that could only happen because of what had come before.

*If you want others to be happy,  
practice compassion.  
If you want to be happy,  
practice compassion.*  
—The Dalai Lama

## Facing the Wall

Her mouth opens for more morphine.  
Eyes close. Index finger touches  
a cross at her throat, head turning  
towards the wall, where I look  
at her four-year-old's cutout art.

A perplexed ladybug with button eyes  
and pipe-cleaner whiskers askew.  
Goldfish that look happy enough,  
though only one is ascending.  
A butterfly dominates in size  
with diagonal red brush strokes.  
on its wings like crossed bones.

Above the art, a black-and-white photo  
of Wynton Marsalis blowing his trumpet  
with a personalized inscription saying  
thank you, though I don't know for what.  
Maybe Wynton felt permission that night  
to play with uncharted feeling.  
Maybe it was one soul recognizing another.

Diagnosed while pregnant, she breast-fed  
only two weeks before chemo began.  
That child's voice fills the room:  
Mommy, are you dying?  
She was, and did, four days later.

Later, the daughter takes a before-bed walk  
with her father. Sees a twinkling celestial body.  
Mommy's saying goodnight to me.  
That light from a now-dead star  
reaches out to her from a long way off.

I think about art on the wall again.  
The self-portrait of a little girl  
with colored hearts on her bathing suit.  
And yes, she is smiling. And the most recent:  
a pink elephant, its trunk hanging low,  
black blobs for eyes—one higher  
as if asking a big question.

—Sandy Scull, Living/Dying Project  
volunteer, writing about his Project client,  
a 47-year-old woman who recently died  
of cancer

First I learned humility, the awareness that nothing I might strive for or achieve will preserve me from the possibility of suffering or the certainty of dying. Secondly, I began opening my heart to those with whom I share this journey, recognizing that they are no more immune to the vicissitudes of life than I am. We are all in this together, doing the best we can to navigate the often-choppy waters of existence.

Of course, compassion for myself was a necessary precedent to finding compassion for others. As long as I was absorbed in my own "drama-trauma" story, I was incapable of real empathy. Service as a volunteer helped me to get out of myself, to begin attending to others.

Finally, gratitude appeared. Gratitude was easy, of course: every person with whom I've worked as a volunteer was younger than I am. Illness and death are not reserved for the old and infirm. Sitting with men and women as they prepared for their own death, I could not help marveling at what a gift each moment is. How could I not feel gratitude for this gift of life?

So humility, compassion and gratitude have become the bedrock of my life, gifts that have come from being of service to men and women willing to share their journey of living and dying. I am honored to attend these folks as they approach their end. All that is required of me is that I be willing, moment to moment, to remain open to them. My experience tells me that when I'm able to simply do that, their journey becomes easier. It also tells me that when I'm able to dis-identify from every story I concoct about who I am and what this journey is about, I become liberated. At that moment the words of the famous Tibetan Buddhist teacher Long chen pa ring in my ears:

*Since everything is but an apparition,  
perfect in being what it is,  
having nothing to do with good or bad,  
acceptance or rejection,  
one may well burst out in laughter!*

—Curtis Grindahl



Flower Depth by Curtis Grindahl

## A PRACTICAL GUIDE TO HEALING

A WORKSHOP FOR CAREGIVERS, THERAPISTS AND  
ANYONE WANTING TO DEEPLY EXPLORE HEALING



Physical healing, emotional healing, spiritual healing, collective healing — the journey to wholeness takes many forms and has as many starting points as there are people who embark upon the journey. Each of us is at a particular point on our healing path, confronting our next challenge, often without clearly knowing whether attitudes or practices we have been using to facilitate growth in ourselves or in our clients are becoming stale, without knowing which direction we should now turn to create meaningful transformation.

In this workshop, we will draw upon the wisdom of Theravada Buddhism and Tibetan Buddhism, the diagnostic message coming from the connection between stages of early childhood development and energetic patterns in the adult body, as well as the softening and passion of heartfelt devotion. Having applied these wisdom traditions during thirty years of being a guide to the dying, a very clear and practical paradigm for the healing path has become apparent to me. Healing occurs through direct contact with the Sacred, through realization of our true nature. There are no shortcuts, but certainly neither taking unnecessary detours nor spending time spinning our wheels can inspire us along what is often a difficult journey.

During this workshop we will explore together a clear, concise and usable model of the healing process that can specifically diagnose and identify the next step that is transformational for each of us, even during crisis. Short, intensive, guided meditations will be presented in order to create a healing experience rather than experience that is about healing. We are all caregivers and are all seekers of healing. These deeply uncertain times offer an incredible opportunity.

There are two training groups available:

EAST BAY	MARIN
<p>SATURDAY, JANUARY 29, 2011      9:00 A.M.—6:00 P.M.</p> <p>ST. JOHN'S PRESBYTERIAN CHURCH 2727 COLLEGE AVENUE BERKELEY, CA 94705-1247</p> <p><b>8 HOURS</b> <b>C.E.U.</b> <b>\$ 120</b></p>	<p>SATURDAY, FEBRUARY 5, 2011      10:00 A.M.—5:00 P.M. SUNDAY, FEBRUARY 6, 2011      10:00 A.M.—5:00 P.M.</p> <p>SAN FRANCISCO THEOLOGICAL SEMINARY      <b>12 HOURS</b> GENEVA HALL, ROOM 100      <b>C.E.U.</b> 105 SEMINARY ROAD      <b>\$ 180</b> SAN ANSELMO, CA 94960</p> <p>FOR DRIVING DIRECTIONS VISIT: <a href="http://livingdying.org/events.html">http://livingdying.org/events.html</a></p>
<p><b>PRE-REGISTRATION IS ENCOURAGED.</b> SPACE IS LIMITED. \$20 EXTRA FOR REGISTRATION AT THE DOOR. CHECKS SHOULD BE MADE PAYABLE TO: LIVING/DYING PROJECT AND SENT TO P.O. BOX 357, FAIRFAX, CA 94978</p> <p>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@livingdying.org">info@livingdying.org</a>.</p>	



Workshops will be conducted by Dale Borglum, Ph.D., who, with Stephen Levine and Ram Dass, 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 Mediator'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 4367. Board of Registered Nursing Provider Number 9621. Courses meet the qualifications for 8 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.

## Prospero's Antiphon

And my ending is despair,  
Unless I be relieved by prayer,  
Which pierces so that it assaults  
Mercy itself and frees all faults.  
As you from crimes would pardon'd be,  
Let your indulgence set me free.

—William Shakespeare, *The Tempest*

## Cide Seculorum\*

Blinded by blazing splendor  
Seeming forever killing out the light  
Life is letting out  
Experience and realization  
To pierce the darkest gates of night.

In faith I rest  
Since casting away fortune and family  
I barter wisdom's lamp for that peace  
Gentle to the night  
Awaiting freedom's flight.

Farewell both delight and despair  
Bound for passage  
To timeless sanctuary,  
hermitage of all that remains.

For what is within shall be without  
All is as always together  
I watch to see  
Listen to know.  
And shed this too forevermore.

—James T. Carter  
Longtime friend of the Project,  
after being diagnosed with ALS

\*To Kill Forever

Lake Manasnovar  
in Tibet by Dale Borglum





## 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.



## Board of Advisors

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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 here and beyond Northern California. The mission of our work is healing, both the healing of that which blocks us from full aliveness and the healing of our collective and individual relationships with death. Fear of death separates us from each other and from our own essential selves. Now as always it is vital to keep what is most meaningful and inspiring to us at the motivating center of our actions.

Our operation is simple and our overhead is minimal. The great majority of our budget comes from individual donations. We ask for your support, financially as well as your blessings and your prayers. Please make a donation in the enclosed envelope, or consider three other ways to support us financially:

☞ First, you can donate to us online using PayPal by going to our website [www.livingdying.org](http://www.livingdying.org), clicking the Supporting the Living/Dying Project link on the left side of the page and then clicking the red Make Donation Now button.

☞ Second, if you shop online, many sites offer a 1%–6% donation to the Living/Dying Project if you first go to [www.goodshop.com](http://www.goodshop.com) and then enter Living/Dying Project in the “enter your charity here” box. Participating sites include: Alaska Airlines, United Airlines, REI, Sears, Allstate, AT&T Wireless, Amazon, the Apple Store, BestBuy, Buy.com, eBay, Circuit City, Office Depot, Macy’s, Nordstrom’s, Toys R Us, Target, LL Bean, Lands’ End, HP, Dell, iTunes, Williams Sonoma, Zappos and many more.

☞ Third, we are a member of the escrip program. Go to [www.escrip.com](http://www.escrip.com) and register. Then 2%–6% of purchases you make at Eddie Bauer, Macy’s, Andronico’s, Delano’s IGA, Safeway, Volvo, Big O Tires, 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).

Our heartfelt thanks to all of you who have supported us in any way. May this holiday season and the year to come be filled with wisdom and blessing for you and for those you love.

—Dale Borglum



## Credits

Once again Steven Englander has done a magnificent job with the layout and design of this newsletter. Steven and Curtis both have been integral parts of the Living/Dying Project for many years and our work is greatly enhanced by their efforts. As well, they are dear men and good friends.