

Living/Dying Project

winter 2007

A Graceful Journey

When I met Denlow and Melissa, all I knew about amyotrophic lateral sclerosis (ALS), the progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord, I'd learned from the deeply moving book *Tuesdays with Morrie*. Written by Mitch Albom, a Detroit sportswriter, the book relates weekly meetings he had with his former professor, who was afflicted with this disease, best known as "Lou Gehrig's disease."

Melissa contacted the Living/Dying Project requesting spiritual support for her husband. I initially visited

them in my role as Intake Coordinator for the Project, but it was clear from this meeting that I would work with them myself rather than refer them to another volunteer. Through weekly meetings and intimate conversations over subsequent months, I was gradually drawn into the circle of family and friends who are part of their journey, a fact for which I'm most grateful. With their permission, I'd like to share what I've discovered thus far.

I learned from the generosity of Melissa and Denlow toward one another that, despite the unrelenting

nature of this disease with its frightening reputation, it is possible to keep one's heart open, and to maintain not only dignity, but also humor. Melissa, the gatekeeper for this unfolding adventure, balances raising a young daughter, maintaining a full-time job at home and managing the never-ending challenges of insuring care for her beloved husband. Whether finding a suitable care provider, arranging a van to take the family to an event or a doctor's appointment, or securing one of the many pieces of high-tech equipment necessary to make Denlow's life easier, Melissa is on top of it. She is the executive assistant everyone wishes they had in their life!

Denlow, the warmhearted fellow in the photo above, revels in his quirky view of reality that features a lifelong affection for clowns and Halloween. (I haven't actually seen the floppy shoes and red nose, but I've been assured he owns them both!) He and Melissa have an unerring capacity for finding humor even in the most challenging of circumstances.

I recall the day Melissa told the story of a dramatic accident the preceding week. A recently hired aide forgot to lock the mechanism used to ease Denlow over the bathtub for his shower. The device toppled over, wedging Denlow between the bathtub and an adjacent cabinet. It was a traumatic moment as Melissa and the aide tried to extricate Denlow.



From the Sideline

From the sideline
From the bench
From my chair
From the other room
I watch and listen

Your delight is mine
And my sadness too
Your laughter raises me up
And drags me down
I'm happy for the pleasure and
the comfort you're given
And I'm envious because it's not
me giving them
I sit wishing it could be me
who tickles
Wishing it could be me who
rough-houses
Lifting you up, twirling you
around
Me, who kisses you, hugging
you tight
Me, who you snuggle while
reading a book
When you fall, I wish I could
pick you up
To kiss your scrapes and bruises
I dream of carrying you piggyback
Or over my shoulder like a sack
of potatoes
How I wish I could show you the
wonder of crayons
The miracle of paint, the imagination
of arts and crafts
Show you the worlds of magic
that await you

Yet I must sit disabled, I watch
from my chair
I listen from where I lie in the
other room
I watch you play from the bench
I wish I could do more than
cheer from the sideline

Later, Denlow spoke of feeling panic at being completely out of control, yet, as Melissa told the story, a smile lifted his lips. I knew instantly that despite the trauma of the moment, he was seeing the humor in the whole episode, something out of a Marx Brothers movie or a Christopher Moore novel perhaps. He confirmed my suspicion and we had a brief chuckle.

When I observed the importance of humor in their relationship, Melissa recalled her mother and her telling Denlow that if he didn't behave, they intended to drop him off in his wheelchair beneath a freeway overpass. I couldn't help but smile at the image and suggested a sign that read, "Will Work for Food."

My time with Denlow consists of both light and serious moments. We share humor, but at heart we're exploring Denlow's relationship with his illness that is gradually diminishing his capacity to engage with life and family. Can he stay open as his body fails him? The question remains before us as the journey continues.

Denlow turned 42 years old in October, celebrating the occasion with his daughter Hannah whose birthday is eleven days before his. Hannah was a few months old when he and Melissa received the definitive diagnosis of ALS. Denlow observed to me during one of our meetings that it has not been lost on him that as his daughter learned to walk, he has been bound increasingly to his wheelchair. And as she learned to talk, speech became ever more challenging for him. At one point, he referred to this disease as a "cruel joke," observing that he retains all his senses, as well as his mental acuity, yet his body makes it impossible for him to act. From the Sideline, one of the poems he shared with me early in our time together poignantly tells the reality of this disease as he experiences it. It brought tears to my eyes.



(It was only when I reviewed this photo later on the day it was taken that I noticed Denlow's hand, immobile on the arm of his wheelchair, as Hannah reached up to give him a tender kiss. I knew immediately the photo belongs with this poem.)

Denlow initially requested that Melissa do everything in her power to extend his life, even if only an eyelash flutters. After a three-year journey, faced with repeated losses of capacity and related freedom, he is now more focused on quality of life than quantity. He also defines healing as something more than physical. During our many conversations, Denlow has spoken of what he is learning along the way. Impatience has finally yielded to gratitude. Despite a history of procrastination, he understands that it is better not to put off what can be done today, including loving those around him.

His busy daily regimen of rising, bathing, dressing, eating, working with massage therapists, a psychotherapist, and an acupuncturist, as well as visitors such as me, demands considerable energy as well as the help of his aide. Even talking is a whole-body exercise requiring coordinated management of limited breathing, a flexing diaphragm, and a tongue and lips that don't always respond faithfully. I commented one day on the vast amount of energy he expends in speaking and he told me that *everything* he does takes effort.

Yet despite the challenges that deepen as time goes on, Denlow continues to express himself through poetry he shares with family and friends. He also shares a visit each week with a close friend to a local movie theatre, the continuation of a lifelong passion for movies. Of course, the journey is made possible only because of his wheelchair and the services of a local transportation company.

At his birthday celebration, I met the circle of friends who love Denlow and his family. They've long appreciated his sense of humor and idiosyncratic view of the world. Last year, when he was unable to decorate their home for Halloween, a favorite pastime of his, friends came and did it with/for him. The occasion was documented by a collection of still photos of each person making funny faces that became a large print, now hanging in their home.

Melissa told me one day that although Denlow worked in an office, dressed in a shirt and tie, he painted his toenails as a statement of his inherent freedom. He chuckled at the realization that he alone knew he was wearing brightly colored toenails as he sat through business meetings. Even the name that so confused me before I met him announces his rebellious streak. His given name is Dennis Enlow, but when he was sent to the principal's office during seventh grade the note was always headed with his name, "D. Enlow." A friend picked up the nickname and he's held onto it his whole life.

So is it irreverence that makes possible such a graceful journey through growing incapacity and an end understood by all? A bit of gallows humor helps, perhaps? No doubt, though it is love and good will, profound respect and trust that inform everything. You can laugh in the face of challenge when the people with whom you laugh care deeply for your well-being. And being well has nothing to do with a long life. Melissa told me one afternoon that her commitment throughout this journey has been to live it with integrity. That doesn't mean perfectly. It does mean doing it with an open heart that extends to the whole community that surrounds their family and offers support.

Perhaps it is not possible to know how they will reach the end of this journey, but it is clear these lovely people have been touched by grace, which they share with everyone around them, including me. Thank you, Denlow, for inviting me to share your journey. Thank you, Melissa, for being the remarkable woman you are. However this unfolds, I plan on being there with you both.



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

*Thus shall ye think of this fleeting world:
A star at dawn, a bubble in a stream,
A flash of lightning in a summer cloud,
A flickering lamp, a phantom, and
a dream.*

—Buddha, in the Diamond Sutra

—Curtis Grindahl

Poorest of the Poor



*You must be the change you
wish to see in the world.*

—Mahatma Gandhi

Gandhi, when asked how we should choose to live our lives, suggested that we ask ourselves “How will our next action affect the poorest of the poor?” In the twenty-first century Western world we still encounter those who are very poor in the material sense of the word, but for many of us, the most pervasive and profound poverty we come into contact with is poverty of the spirit—depression, divisiveness, fear, anger. Whether we look to our current political climate, at our neighbors as they attempt to rush ahead in traffic, into our own homes or even within our own hearts, how easy and comforting it is to be critical of “poor” behavior.

Philo of Alexandria said “Be kind, for everyone you meet is fighting a hard battle.” Yet even with the best of intentions, trying to be kind is overwhelmed again and again by our deeper needs and fears. We are all poor before God until we realize our oneness with Her/Him. The essence of our healing journey is the movement from a struggle to understand and improve, to the surrender into contact with the Sacred, the Sacred that is our Essential Self.

Eventually being Compassion rather than trying to show compassion becomes our stance in life. Eventually we truly believe Christ’s words that the Kingdom of Heaven is within and is available to each of us right now. Finally we surrender to the truth that we are the Beloved. Compassion is our true nature. All spiritual practice, all psychotherapeutic healing, leads to this fundamental realization. The totality of our passion fully engaged.

Yet until we are willing to look death directly and unflinchingly in the face, our passion will be subverted by our fear of death. Fear of death exactly equals lack of spiritual freedom, lack of enlightenment. As long as there is an enemy within or without, the struggle will be endless. How alive are we willing to be? Is anything lacking?

Confronting and eventually healing our fear of death brings us to the joy that transcends happiness and sadness, wellness and illness. Is the tumor in our body that might eventually kill us also a form of the Sacred? Can we become whole without directly contacting the Sacred and realizing our identity with the Sacred?

For many of us in the physically fixated modern Western society, the most direct and accessible route to realization of our oneness with the Beloved is a twofold path. First, heal our fear of death by coming into intimate contact with death or with our fear of death. Second, really feel the suffering on the nightly news or volunteer at hospice or get cancer or have a loved one who dies.

Follow these paths with as much attention and openheartedness as possible. One of my first meditation teachers, Trungpa Rinpoche, said that one would always remain a dilettante on the spiritual path until one became truly intimate with death. Second, because most of us come from Judeo-Christian roots, which is essentially a devotional tradition, find a practice to cultivate devotion. Pray, meditate, call out, burn. The combination of these two paths is most potent medicine in these conflicted times.

—Dale Borglum

*By means of all created things,
without exception, the divine
assails us, penetrates us and
molds us. We imagine it as
distant and inaccessible,
whereas in fact we live
steeped in its burning layers.*

— Pierre Teilhard de Chardin

*I praise what is truly alive,
What longs to be burned to death.
A strange feeling comes over you
when you see the silent candle burning.
Now you are no longer caught
in the obsession with darkness,
and a desire for higher love-making
sweeps you upward.
Distance does not make you falter,
now, arriving in magic, flying,
and finally insane for the light,
you are the butterfly and you are gone.
And so long as you haven't experienced
this: to die and so to grow,
you are only a troubled guest
on the dark earth.*

—Goethe, from *The Holy Longing*,
translated by Robert Bly



*The Way is perfect, like vast space where
nothing is lacking and nothing is in
excess. Indeed, it is due to our choosing
to accept or reject that we do not see the
true nature of things.*

—Third Chinese Patriarch



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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Have patience with everything unresolved in your heart and try to love the questions themselves as if they were locked rooms or books written in a very foreign language. Don't search for the answers, which could not be given to you now, because you would not be able to live them. And the point is to live everything. Live the questions now. Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer.

—Rainer Maria Rilke, *Letters to a Young Poet*

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 the healing of our collective and individual relationships with death and hence with our lives. This often is the most immediate and direct means to mending that which divides us from our neighbor. 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. A great majority of our budget comes from individual donations. We ask for your support, financially and along with your blessings and prayers. Besides making a donation in the enclosed envelope, there are two other ways to support us financially.

- ☞ First, we are a member of the escrip program. Go to www.escrip.com and register. Then 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).
- ☞ Secondly, you can shop at Under One Roof, a gift store at 549 Castro Street in San Francisco and also at www.underoneroof.org. 100% of their profits go directly to 35 agencies (including us) in the Bay Area that offer support to people with AIDS. Under One Roof offers a tastefully selected inventory of home décor and personal items.

Last year, we received many gifts and donations, including a generous grant from the Betsy Gordon Foundation. Our heartfelt thanks to all of you who have supported us financially and/or with your kind thoughts and prayers. 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

Heartfelt thanks to Steven Englander of Interface Design, 415-388-7744, who once again beautifully designed this newsletter. Steven has been a dear friend and a part of The Living/Dying Project for many years.

Photos & Illustrations: pages 1 & 2: Enlow Family by Curtis Grindahl; page 4: Tree of Creation ©Cari Buziak; page 5 top: Bressman Cabin, built in 1880, Elko County, Nevada ©George Ward; page 5 bottom: Nicasio Valley, Marin County, California by Curtis Grindahl.