

Living/Dying Project

2007 - 2009

I've brought together articles published in three consecutive Living/Dying Project newsletters describing the journey taken by one of our clients, Denlow Enlow, that I witnessed/shared as a volunteer with the Project. I thought it would be beneficial to have the full story in one document that can be easily shared with those interested in the work of the Project. I've little doubt readers will be as touched by this man as I was. I've taken this opportunity to incorporate color photos rather than the black and white used in the printed newsletter.

— Curtis Grindahl

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

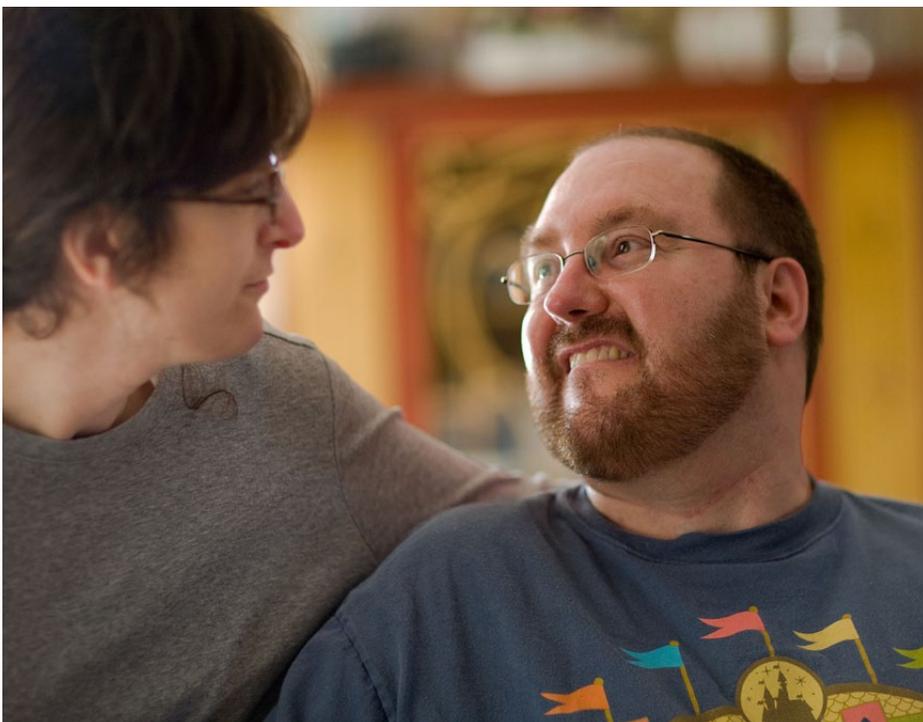
for her husband. I initially visited them in my role as Intake Coordinator for the Project but it was clear from this meeting that I would work with them myself rather than refer them to another volunteer. Through weekly meetings and intimate conversations over subsequent months, I was gradually drawn 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 humor. Melissa is the gatekeeper for this unfolding adventure who 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 it is 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 you see in the photo on the left, revels in his quirky view of reality that features a life-long 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 when a recently hired aide forgot to lock the



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

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.

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 some time later, 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 has become 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



(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.)

impossible for him to act. 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.

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 to not 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, psychotherapist, 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 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 *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 life-long 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, his idiosyncratic view of the world. When he was unable last year 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 ended up in a large print now hanging in their home.

Melissa told me one day that although Denlow worked in an office, dressed in 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 young 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.

— Curtis Grindahl



*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 lightening in a
summer cloud.
A flickering lamp, a
phantom, and
a dream.*

— Buddha, in the
Diamond Sutra

The Journey Continues

A year has passed since I wrote about Denlow Enlow in last year's newsletter. Melissa Enlow contacted the Living/Dying Project in 2007 to ask for spiritual support for her husband, who had been diagnosed with Lou Gehrig's disease, ALS (amyotrophic lateral sclerosis). We've been meeting once a week for over a year and a half.

*Pathwalker,
There is no path,
You must make the path
As you walk.*

— Antonio Machado

Denlow's journey continues. As we've all expected, his capacities have diminished as his body succumbs to the reality of this unrelenting disease. Though Denlow's mind remains sharp and his insights evocative, words are harder to form, whether he speaks them or composes them on the computer.

His breathing is much diminished and his fingers more difficult to control but his writing is as moving as ever. We've included a recent poem entitled **My Four Corners**. As he and I have discussed his imminent death, Denlow expressed a wish that his ashes be scattered at the "four corners of his life."



Sitting at the computer with Denlow and reading this and other poems as they slowly emerge from his still vital and creative mind, I'm struck by the depth of these words. I know his story well enough after hours together that I appreciate how each word resonates with the fullness of a life that, though coming to an end, has been richly lived.

It is perhaps the fact I've spent so many months with Denlow, though I'm inclined to believe it has more to do with the sweet presence of this man, that have made our meetings so precious to me. I feel as though Denlow has been teaching me how to open my heart in the face of loss in ways I hadn't imagined possible. His living in the face of dying is inspiring. I love him dearly and thank him for the gifts he continues to give me.

Melissa recently asked if I'd be willing to officiate at the memorial service for Denlow after he dies. I was deeply honored and accepted. Since then Denlow and I have been preparing for the service in a conversation that is at times filled with humor

and at other times great sadness as he contemplates saying farewell to everyone and everything he loves. Living with dying is not an easy thing to do, yet it can be remarkably precious.

— Curtis Grindahl

*My continuing passion is to part a
curtain, that invisible veil of indifference
that falls between us and that blinds us
to each other's presence, each other's
wonder, each other's human plight.*

— Eudora Welty

My Four Corners

My East

Scatter my ashes there
Where my life began
Where my seed began to germinate
That land where the three rivers meet
High up the river so that I will float down
Past all those places I played as a boy
Those precious pools of innocence
Back to my beginning, scatter me there

My South

Scatter my ashes there
Where my character developed
Where I finally took root
That valley beneath those golden bluffs
Under the cedar, where my mother spirit rests
In memory of times so happy and creative
I learned much about the world, myself as well
Back to my enlightenment, scatter me there

My West

Scatter my ashes there
Where I found my love
Where my universe blossomed
That hill with its hallowed halls of higher learning
Under the oak in the meadow, where I reveled free
A bacchanal with memories that will last lifetimes
Friendships forged, bonds unbreakable, love everlasting
Back to less troubled times, scatter me there

My North

Inter my ashes there
Where my life draws to an end
Where my life grew into fruition and went to seed
That land north of the bay where the sleeping maiden lay
In those valleys below my heart found its home
My perfect home, my beautiful wife and daughter, my love
Hopefully, I leave enough behind, my legacy of words
Take me to my ending, inter me there

— Denlow Enlow 8/25/08





Denlow and his hospice nurse, Andrew Getz

The Journey Ends

Denlow Enlow died on March 18, 2009, after four years struggling with the ravages of Lou Gehrig's disease, ALS. Those who've been following his journey over the last two years in the pages of the Living/Dying Project newsletter are aware that Denlow was a remarkable man who met the challenges of his disease with grace and good humor.

During the final six months of his life Denlow focused his energy on preparing for the end. Most important to him was recording for his young daughter Hannah who her father was. His diagnosis happened shortly after her birth, consequently his illness was very much part of her life from the beginning. He'd witnessed with sadness the space that had been growing between them as Hannah's life took her outside of their home and his growing incapacity made it ever more difficult for him to engage with her when she was at home. He hoped to document his life through photos, videos, music and the written word. The final months of his life he devoted his limited energy to finishing a project that in reality could never be finished. There was simply too much to say.

He also worked with me during those months to prepare for his memorial service. We reviewed his poetry to see what might be suitable to the occasion. He explored his extensive collection of songs, creating a playlist he called "The Mourning After." We laughed and we cried as we reflected on the fact of this end to his life.

The focus of my work with Denlow throughout the time we met together was quite simply encouraging him to remain open in the face of whatever was happening in his body as it gradually failed him. Early in our meetings Denlow focused on the fear of being breathless, of essentially suffocating. The subject occupied his dreams and eventually his poetry. He wrote about a snake wrapping its body around him after it had paralyzed him, then squeezing the breath and life force from his body. Those fears gradually diminished but as his breathing became labored and occasionally failed him, the challenge remained to keep open to each moment. Denlow did so with remarkable grace.

The day Denlow died was a day I was scheduled to meet with him. I'd agreed to offer respite to Denlow's beloved caregiver Joe after Melissa returned to working a few days each week at her employer's office. For the first few years of their journey together, Melissa had telecommuted from home, so she was always available to give Joe a break. Providing "chair side" nursing support is not typically part of being a volunteer with the Living/Dying Project and I certainly had some apprehension the first day I assumed my new duties. Yet, I was aware when Melissa asked if I were willing, that the bond of love that had grown between Denlow and me over the years we'd been meeting, made it easy to say yes.

On this particular day, however, the paramedic's van pulled up

When we fight with our failing, we ignore the entrance to the shrine itself and wrestle with the guardian fierce figure on the side of good.

— David Whyte



just as I arrived. I didn't know precisely what had happened but I was aware there had been many emergency visits in the past. I led them to where I expected Denlow would be waiting. He was seated in his wheelchair gasping for breath, a mask over his face as Joe attempted to give him relief with bottled oxygen. The paramedics quickly determined that Denlow needed to go to the hospital. I followed and after convincing hospital staff my presence might be helpful to them since he couldn't communicate without his computer, they permitted me to join Denlow in the emergency room.

Clearly, I had nothing to contribute to this moment apart from the relationship Denlow and I had created over the hundreds of hours we'd spent with one another. I stood at his shoulder, my hand on his arm or holding his hand. I was able to tell hospital staff what I knew of his condition and directed them to Melissa for more detailed information. Beyond that I simply gazed into Denlow's eyes and encouraged him to remember that he was more than this body that was failing him at the moment. With the efforts of the staff and perhaps my calming presence Denlow was gradually able to calm down. When Melissa arrived an hour later it seemed Denlow had stabilized and that this latest episode would conclude without further incidence. Before leaving I spoke with Melissa about coming to meet with Denlow in two days.

I received a call from Melissa later that same evening. She told me Denlow had died in his bed shortly after returning from the hospital. I immediately drove to their home and joined her in Denlow's room. I noted the photo of me he'd taped to the wall next to his bed as I rested my hand on his

now cold head. The journey had finally come to an end. Melissa and I comforted one another.

As Melissa and I collaborated to prepare the memorial service she spoke of her loss. In truth, Denlow's passing represented a relief for her and her family. I knew from my time in their home how extraordinarily hard she'd worked to provide the care her husband needed. She spoke of how her loss was truly for the man whom she'd married and with whom she'd shared the years before his diagnosis with ALS. She had been grieving that loss throughout the years of his illness.

I never knew Denlow when he was healthy, so my grief was for the man in the wheelchair whom I visited each week for two years. He became a beloved presence in my life. I still think of him every Friday. Sharing his journey was a great gift for which I will always be grateful.

— Curtis Grindahl



Praying

*It doesn't have to be
the blue iris, it could be
weeds in a vacant lot, or a few
small stones; just pay attention, then
patch*

*a few words together and don't try
to make them elaborate, this isn't
a contest but the doorway
into thanks, and a silence in which
another voice may speak.*

—Mary Oliver



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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Denlow's final poem...

Terminal Velocity

As I reach my terminal velocity
Each day renewed, I fall the same distance daily
Incrementally closer to my destination

My screams, my prayers and my laughter
All fall behind me as I plummet towards the earth
I am falling faster than the speed of sound
A skydiver sans parachute to slow my descent
Wind whips my flesh, roars in my ears
The cold nips at my skin, numbing my body
Gravity pulls me down and the air pushes me up
Paralyzing my body between the two forces

There is a calm that rests within
An acceptance of the inevitable
I do not fall without emotions, those rest inside
I am not a dead weight, I am alive inside
Each moment of my fall, I live in that moment
I am aware of my forward momentum, yet I fall

I have reached my terminal velocity
Each day when I open my eyes, I fall the same distance
again
Incrementally closer to my final destination

— Denlow Enlow 8/25/08



Photo Credits

Curtis Grindahl: It Must Be Love (page 1); Denlow and Hannah Kiss (page 2); Denlow Smiles (page 3); Denlow in Skull Shirt (page 4); Denlow and his nurse, Andrew (page 5); Pacific Sundance (page 6).

Steven Englander did a magnificent job with the layout and design of these newsletters. I incorporated his basic design as well as graphics and additional text suggested by Dale Borglum, Executive Director, but most importantly friend, with only slight modification.