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A perfect day: the sunset of a meaningful life

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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THURSDAY, MAY 20, 2010

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To live at risk for Huntington's disease means to partake of a world with frequent news of premature death. Naturally, those of us in the HD community feel a deep need to recognize the significance of those who have passed. For a gene-positive person like me, these deaths bring on especially profound sadness and yearning for meaning.

HD is incurable. It inexorably destroys the brain, in the end leaving its victims completely dependent on others for eating, personal hygiene, and getting about. It generally strikes people in the prime of life, and, in about ten percent of cases, it affects children and teens. Life expectancy after onset is ten to 20 years.

HD also devastates the families who care for their loved ones during the agonizing demise of each HD person. It's hard to imagine a job description more difficult than that of "HD caregiver."

Many have an extremely difficult time; some become exhausted and must seek out an institution that can provide specialized care. But many others rise to the occasion, displaying a level of concern and commitment that seem to belong to another world.

They do it all with – and because of – the most powerful force in the universe: love.

Unrelenting fear

My mother died of HD in 2006 at the age of 68. If it weren't for HD, she would be thriving today at the age of 72. Her mom lived to 87 and was healthy until the final months of her life.

My late father took care of my mother for more than 15 years. He was a Huntington's disease warrior, like the thousands of other individuals who awake every day to bathe, dress, feed, and assist their stricken companions. Married at 30, he might not have died last September at 81 if he still had my mother as a healthy companion.

Since my mother's passing, every time I learned of the decline and death of HD people, it pounded unrelentingly upon my conscience like a workman's steady and certain hammer. Each blow reminded me of Mom – and of my own status, what the scientists call a "premanifest" condition.

Deaths like barbs in the heart

In recent months, the word of deaths and worsening symptoms in other patients has become even more painful, like a staccato of painful barbs in the heart.

Late last year Emily Krull of Orange County, CA, died of complications from juvenile Huntington's disease and another malady. She was 20.

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Emily and her parents had worked hard to raise awareness about HD (click here to read more).

On February 16 of this year 13-year-old Karli Mukka died of HD in Michigan.

A couple weeks ago I learned that a boy with juvenile Huntington's got a feeding tube – often a sign that death is not too far off. In the final months of my mother's life, my family decided against one for her.

A few days ago Dan Byers, the uncle of HD activist and author Susan Elaine, succumbed to the disease. A resident of the Bay Area in California, he was 67. A graveside memorial service will be held for Dan at 11 a.m. on May 21 at Holy Sepulchre Cemetery, 26320 Mission Boulevard, Hayward, CA.

And, very close to home for me, Steve Topper of San Diego ended his long fight against HD on April 7. He was 66.

Steve and Gayle: laughing a lot

Steve's death hit me particularly hard. Steve was diagnosed with HD in August 1997 – less than two years after I learned of my mother's condition. Not long thereafter I met Steve and his wife Gayle Tinnerman at the local HD support group.

Steve, who was divorced from his first wife, had met Gayle at a dance in 1990. Before HD disabled him, he worked as a cogeneration engineer, assisting companies with large demands for electricity to generate their own power. His consulting business took him as far off as Australia, and he also worked close to home on projects such as the one he did with Sea World in San Diego.

Steve on New Year's Eve, 1990 (family photo)

Steve loved sports cars, and he and Gayle were enthusiastic fans of the San Diego Padres and especially the San Diego Chargers.

Steve had three children from his first marriage and also four grandchildren. His daughter tested negative for HD. His elder son has

already developed the disease and is on disability. He has two children. Steve's second son is untested.

Steve and Gayle, my wife, and I were regulars as all of us in the group struggled to cope with the many facets of HD, which involved the affected like Steve, the at-risk like me, and caregivers like Gayle, and the potential caregivers like my wife.

Unlike many HD patients, who seem to withdraw into an inner world that nobody can fathom, Steve was very effusive. Always smiling, in the early years of the disease he wanted to talk to other people and shake their hands.

What also struck me – and what I could not understand for a long time because I couldn't face HD's effects on my mom – was Gayle's complete devotion to Steve. She doted on him, but never became condescending or showed pity.

In fact, Steve and Gayle laughed a lot. Though it may seem unimaginable in the face of such a horrible disease, they brought hope and joy to the support group.

Steve and Gayle (family photo)

The wisdom of a devoted caregiver

In my files, going back to 2002, I have some 20 pages of e-mail exchanges with Gayle regarding Steve's care, what I might do to avoid onset of the disease, and other information about HD.

Probably Gayle's most memorable message – one from which I learned great humility, wisdom, and insight – responded to an article that I had written about an HD patient for the newsletter of the San Diego chapter of the Huntington's Disease Society of America (HDSA-San Diego) in April 2003 (click here to read more).

"VERY well written – such a lot of work!" she wrote. "[But] I must take

umbrage with the generalization that HD people do not smile or laugh much.... After I read the article, every time Steve laughed or smiled this weekend, it 'registered' with me – I make great effort to joke and be silly and have fun with Steve. It's pretty easy with him 'cause that's his general nature. He, also, has many moments of frustration, etc. BUT he enjoys many moments and loves to laugh and be happy."

Gayle added that she wasn't interested in a "pity party" for herself. She *wanted* to care for Steve. Watching the two of them together, I understood that they simply enjoyed each other's presence.

Reading Gayle's words, I recognized how I had often avoided engaging with my mother after she could no longer converse. I also began to understand how my deep fears of the disease led me to minimize contact with other HD patients. I began to see the importance of valuing HD people as human beings even as they lost great portions of their adult capacities.

Yes, HD dehumanizes people more than any other disease. But, observing Gayle and Steve, I learned that we must love HD patients just as we did when they were healthy. And we must honor them for their struggle.

Gayle's determination

Gayle always tried to bring hope for to Steve's condition. She drove him long distances for doctor's appointments and tirelessly researched dietary supplements and potential drugs.

In 2002 and 2003, Gayle, who at the time was working for LawInfo.com, arranged for the company to build the first professional website for HDSA-San Diego. LawInfo hosted and maintained our site through April 2009.

In October 2003, Gayle published an article in the chapter newsletter titled "Waiting for a cure: new group says we shouldn't." The article presented the argument of Dr. LaVonne Goodman's Huntington's Disease Drug Works (HDDW) program. Dr. Goodman advocated a "treatment now" approach involving the use of supplements and non-HD medications that had been lab-tested for safety and possible efficacy in Huntington's. Gayle and I traveled to an informational meeting held by Dr. Goodman in San José, CA.

Both Steve and I adopted the daily HDDW regimen, as did other patients around the country. I haven't missed more than a day or two since. Some HD researchers are skeptical of this regimen, but I have already reached 50 with no apparent symptoms. My mom seemed to exhibit the first symptoms around age 48.

Enjoying life

Gayle and Steve knew that HD would cut short their time together. Even

though he steadily declined, they enjoyed life as much as they could by traveling, going on outings in San Diego, and eating at restaurants.

Steve and Gayle at Fisherman's Wharf in Monterey, CA, in 1998 (family photo)

This way of facing the disease reminded me of my own parents. They continued to travel every year or so to Las Vegas from our hometown in the Midwest. Even though my mom lost the ability to communicate, she loved to play the slot machines.

Gayle and Steve's other big pastime – and health strategy – was walking. Walking provides crucial aerobic exercise to supply the brain with oxygen and keep the body fit and limber. Gayle worked with Steve's physician to find ways to keep him walking as long as possible.

"You should have seen him on our daily walk, which we just finished," Gayle wrote me in an April 2003 e-mail. "He said during the walk, 'Am I zooming?' He was trying to walk faster. I, of course, said he was. He actually was definitely walking 'faster' than normal – which was slow for most people, but faster than normal for him."

Steve undergoes physical therapy with Zuri Pineda in 2004 (photo by Gayle).

Losing mobility

Sadly, however, Steve gradually lost his mobility – one of the most devastating symptoms of HD. Gayle recorded the most terrible moments in the decline: no longer able to dance (December 1999) and then walk (November 1, 2005).

The last time I saw Steve, Gayle pushed him in a wheelchair into a restaurant for a lunch with Dr. Goodman of HDDW. In February of this year he could no longer feed himself.

A peaceful death

On April 19, I called Gayle after receiving an ominous-sounding e-mail. She confirmed my worst expectation, although, knowing the ways of HD, I was not surprised. In early April Steve stopped eating. He knew his time had come. He remained at home.

Gayle, Steve, and a few close friends and relatives kept laughing and joking with Steve until the very end.

At one point they took his wheelchair out of the room and repeated to him that in heaven there would be no wheelchairs.

On April 7 he died peacefully.

The pleasure of Steve's life

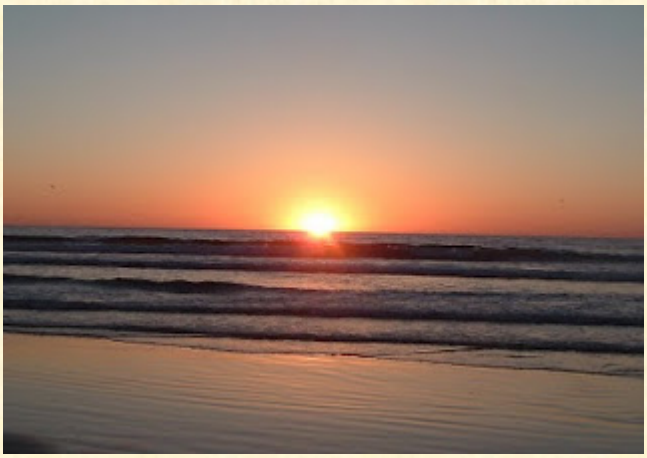
On April 24, Gayle, Dr. Goodman, family, and friends attended a memorial service for Steve near the ocean in the beautiful La Jolla area of San Diego. After the service, they got into kayaks and carried Steve's cremated remains out to sea.

"Then out for the kayaks – wow!" Gayle wrote me a couple days later. "It was exhilarating and so peaceful once we got past the surf. We banded together and held each other's kayaks, and Steve's brother Joe spilled the ashes out into the sea and Jocie (Steve's daughter) threw out the 12 pink roses. I will never forget looking back to the beach with the roses floating over the water over the sinking ashes – I was overwhelmed by the finality."

Gayle, in front of red boat, and Steve's son David, in rear, head out to see with his ashes (family photo).

Gayle prepared a memory book with photos of Steve, family, and friends and commentary about his life. “In Memoriam and Celebration. Stephen William Topper. The pleasure of your presence,” Gayle wrote on the cover.

Near the back, Gayle placed a color photo of a cloudless Pacific sunset taken the evening of Steve’s passing. On the photo Gayle superimposed these words: “It’s such a perfect day – I’m glad I spent it with you.”



Posted by Gene Veritas at 10:25 AM

3 comments:

Rob Millum said...

Gene what a great remeberance of Steve and Gayle. This article is also a good primer for those of us who are not caregivers but have experienced the same shyness and feelings of not knowing exactly how best to relate to those affected with the disaese. I for one will do my best to encourage laughter after reading this article!

5:18 PM, May 20, 2010

Anonymous said...

Wow! Words can't describe such a beautiful relationship . My brother struggles daily with HD but keeps on fighting.

8:46 AM, May 21, 2010

Anonymous said...

Beautifully written. Thank you so much for your work. You are helping everyone effected by HD. May God bless you and your family.

9:01 AM, May 24, 2010

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