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8-9-2014

Making the threat of Huntington's disease 'small stuff'

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Serbin, Kenneth P., "Making the threat of Huntington's disease 'small stuff'" (2014). *At Risk for Huntington's Disease*. 188.

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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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About Me

 [GENE VERITAS](#)

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SATURDAY, AUGUST 09, 2014

Making the threat of Huntington's disease 'small stuff'

To reduce anxiety about the threat of Huntington's disease, I start each day with a deep breathing exercise and meditation.

I started developing this practice in late 1997, two years after learning of my mother's diagnosis for HD and the devastating fact that I had a 50-50 chance of inheriting the mutated gene. After many months struggling with worry and denial, I had hit rock bottom emotionally. (I eventually tested positive for the HD mutation.)

Browsing at titles in a bookstore – bookstores mattered a lot more before the e-book explosion – I came across *[Don't Sweat the Small Stuff... and it's all small stuff: Simple Ways to Keep the Little Things from Taking Over Your Life](#)*, a bestseller by the late [Richard Carlson, Ph.D.](#)

Over the next few months, I studied the book's 100 brief chapters, each prescribing how to achieve calm in our harried world. Some might consider self-help books shallow, but I found this one to have a core of wisdom.

Chapter 1, "Don't Sweat the Small Stuff," lays out Dr. Carlson's basic philosophy, a combination of Judeo-Christian fraternal love with a Buddhist de-emphasis of the desire for material success.

"Often we allow ourselves to get all worked up about things that, upon closer examination, *aren't* really that big a deal," Dr. Carlson wrote. "We focus on little problems and blow them way out of proportion.... So many people spend so much of their life energy 'sweating the small stuff' that they completely lose touch with the magic and beauty of life. When you commit to working toward this goal you will find that you will have far more energy to be kinder and gentler."

Getting calm with deep inhalation

Chapter 63, "Count to Ten," was pivotal for me.

"When you feel yourself getting angry, take a long, deep inhalation, and as you do so, say the number one to yourself," Dr. Carlson suggested. "Then, relax your entire body as you breathe out. Repeat the same process with the number two, all the way through *at least ten* (if you're really angry, continue to twenty-five)."

The deep breathing "clears your mind with a mini version of a meditation exercise," he explained. It increases the oxygen in your lungs, reduces anger, and provides perspective, making "big stuff" look like "little stuff."

With time I settled on 20 deep breaths for every morning, followed by a few minutes of quiet relaxation. I usually sit in a lotus position on a carpet

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

or on the edge of a chair or couch with my back arched forward to get the air as deeply into my lungs as possible.

When family or work obligations occasionally make it impossible to meditate at home, I do my breathing while driving or in airports.

When I *don't* meditate, my day almost always becomes more stressful, sometimes even sad.

The breathing provides a powerfully calming effect. I feel that I'm doing something good for my brain by increasing the oxygen. By reducing my overall stress level, I hope, I can help delay the onset of HD symptoms.

In the video below, you can watch the demonstration of the technique I gave at the start of my [keynote speech](#) at the 2011 HD Therapeutics Conference, sponsored by the CHDI Foundation, Inc., in Palm Springs, CA. Other members of the HD community as well as caregivers and counselors engage in or recommend similar exercises, and a vast bibliography exists on yoga and meditation techniques. The principles here can apply for *everybody* in *any* aspect of life.



Coping with Risk for Huntington's Disease by Meditating

from [Gene Veritas](#)

05:24 |



[Coping with Risk for Huntington's Disease by Meditating](#) from [Gene Veritas](#) on [Vimeo](#).

Increased anxiety, new insights

The past couple years I have included in my meditation a reading from [Living Faith: Daily Catholic Devotions](#). Resonating with many of Dr. Carlson's points, *Living Faith* helps me tap my spiritual dimension, longstanding since my childhood in the Catholic church, and contemplate the mysteries of suffering and the Creator's love.

Over the past couple years, now well beyond the age at which my mother's symptoms started, I've become more anxious about HD as well as things in general. So, early this year, I decided to add a daily reading from *Don't Sweat the Small Stuff* to my morning meditation.

A couple weeks ago, I finished.

Rereading *Don't Sweat the Small Stuff* brought back warm memories of how I had overcome difficult moments, including depression, in those early years after my mother's diagnosis – including my own positive test for the HD mutation in 1999.

It also revealed how I've usually dealt successfully with the ongoing challenges of living at risk. Rereading the book reinforced the lessons I had learned. It also provided me with new insights.

Some of my favorites are: Chapter 6, "Remind Yourself that When You Die, Your 'In Basket' Won't Be Empty"; Chapter 16, "Ask Yourself the Question, 'Will This Matter a Year from Now?'; and Chapter 66, "Think of What You Have Instead of What You Want."

Problems as teachers

Two chapters in particular have helped me reflect on HD: Chapter 17, "Surrender to the Fact that Life Isn't Fair," and Chapter 75, "Think of Your Problems as Potential Teachers."

"One of the *nice* things about surrendering to the fact the life isn't fair is that it keeps us from feeling sorry for ourselves by encouraging us to do the very best we can with what we have," Dr. Carlson wrote. "We know it's not 'life's job' to make everything perfect, it's our own challenge."

Regarding problems, he wrote: "Rather than push away the problem and resist it, try to embrace it. Mentally, hold the problem near to your heart. Ask yourself what valuable lesson(s) this problem might be able to teach you."

Humility, acceptance, and hope for treatments

This is solid advice. However, isn't a deadly genetic brain disorder like HD truly "big stuff" that just can't be meditated away?

I've thought a lot about this question as I reread *Don't Sweat the Small Stuff* and corresponded with HD-affected friends. They are struggling with the loss of their mental and physical abilities; they can no longer work or drive and need help from others for the simple tasks of daily living.

Recently I also attended the wake for an old friend who died in his early 60s of pancreatic cancer, a mainly incurable condition. I didn't know he was ill, so his death came as a shock.

I imagine my own HD symptoms, watching myself quietly fade away, losing the ability to write, teach, and engage with my family as we guide our daughter through high school and start thinking of retirement.





That is big stuff!

However, I try to make it as small as possible. When I'm not resorting to my old friend denial – which becomes harder as I approach the inevitable onset – I reflect on two of the key lessons taught by Dr. Carlson and the authors of *Living Faith*: the need for humility and acceptance.

I *will* die. As I witnessed with my mother, HD is a horrible way to go.

However, until onset I will adhere to Dr. Carlson's Chapter 100: "Live This Day as if It Were Your Last. It Might Be!"

As both Dr. Carlson and *Living Faith's* authors would agree, living life in that manner includes making the world a better place and engaging with family, friends, and many others. I may die of HD, but the collective work of advocates like me, together with the scientific community and friends and supporters, may help make HD "little stuff" in the future by furnishing effective treatments.

Posted by [Gene Veritas](#) at [10:51 PM](#)     

Labels: [anxiety](#) , [brain](#) , [deep breathing](#) , [diagnosis](#) , [Don't Sweat the Small Stuff](#) , [Huntington's disease](#) , [meditation](#) , [Richard Carlson](#) , [symptoms](#) , [tested positive](#) ,

[treatments](#) , [yoga](#)

5 comments:



Unknown said...

A really interesting and thought provoking blog again. Thank you. I am a great believer in not sweating the small stuff, but find it difficult to put into practice at times.

[10:48 AM, August 10, 2014](#)

Anonymous said...

I really enjoyed this blog article. I have been struggling to find some way of coping with HD, and recently thought yoga and meditation might help. Thank you for inspiring me to pursue ways of minimizing the stress/worry. I will check out the book you recommended as well. I need something to keep me focused on enjoying the present and it sounds perfect.

Please feel free to contact me (samplesally@outlook.com). You are such an inspiration.

[10:23 AM, August 11, 2014](#)

Anonymous said...

I enjoyed your blog and learned.
Thank you for sharing

[4:49 PM, August 15, 2014](#)

Anonymous said...

From Buddhist perspective the disease is karma, to change it can be done by doing good karma such as helping others, recite mantras and prayers, meditation practice that will all benefit. The future is not predestined and you can make it better by good karma. Om Namu Buru Buddha Gyani.

[10:40 AM, December 27, 2014](#)

Anonymous said...

Anonymous post about "Buddhist perspective" is totally wrong!

First: Reciting mantras and prayers will bring you nowhere.
Second: Karma does not work that way

Unfortunately, most people just dont know what Buddhism actually is teaching..

[3:48 PM, October 12, 2015](#)

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