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2-8-2016

The little things that are really big: caregiving in families with Huntington's disease

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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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MONDAY, FEBRUARY 08, 2016

The little things that are really big: caregiving in families with Huntington's disease

The everyday kindness of the back roads more than makes up for the agony of the headlines – [Charles Kuralt](#)

As a member of a Huntington's disease family, I have become deeply familiar with the common yet often unheralded human practice of caregiving.

My "HD warrior" father Paul Serbin cared for my HD-stricken mother Carol for more than a decade.

My mother died ten years ago this week. Her passing sent me into a months-long dual spiral of anxiety and depression: I had inherited the HD gene from her, and seeing her demise provided a portent of my own future ([click here](#) to read more).

Because of the inevitability of HD onset, I know that I too will require caregiving.

Furthermore, as a father, I've spent the past fifteen years helping my wife Regina raise our daughter Bianca, a special form of caregiving. Bianca tested negative in the womb, thus avoiding the specter of juvenile Huntington's. As we teach her to drive and begin discussions about college, our role as parents becomes both more rewarding yet more complex.

Three weeks ago, the balance shifted, as Bianca and I became temporary caregivers for Regina: she underwent an operation to repair a torn rotator cuff and must keep her right arm in a sling for at least six weeks.

Completely interdependent

Caregiving is about all of the little – but really *big* – things we humans do for each other.

It's how families, hospitals, and nursing homes run.

We are completely interdependent.

As we've helped Regina over the past several weeks, the meaning of caregiving has become ever more clear to me.

It involves small but important tasks: bathing her, spraying on deodorant, buttoning her shirt, adjusting her sling, driving her to doctor's and physical therapy appointments, taking over her share of car pool duties, providing assistance in the kitchen, exercising her disabled arm – these and many more tasks have highlighted for me the importance of caregiving, taught me to be more sensitive to Regina's needs, and reminded me of what's most important in life.

[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
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[Heather's Huntington's Disease Page](#)

Despite a busy high school life, Bianca has helped out, too.

It's brought us closer together.



Bianca (left), Regina, and Kenneth Serbin (aka Gene Veritas) (photo by Bianca Serbin)

Valid and important emotions

I'm certainly no saint. I've done my share of grumbling! And sometimes I feel overwhelmed.

As I've learned from news items posted on Facebook HD discussion pages, caregiving experts say it's okay to experience feelings associated with caregiving such as anger, boredom, frustration, and impatience.

"Whether you become a caregiver gradually or all of sudden due to a crisis, or whether you are a caregiver willingly or by default, many emotions surface when you take on the job of caregiving," a recent article at *Dementia Today* states. "Some of these feelings happen right away and some don't surface until you have been caregiving for awhile. Whatever your situation, it is important to remember that you, too, are important. All of your emotions, good and bad, about caregiving are not only allowed, but valid and important."

As [another article](#) suggests, caregivers need to face emotions directly, find healthy ways to release anger, share feelings with close friends, and take breaks to pursue enjoyment.

These recommendations can apply to short-term caregiving situations such as recovery from an operation but also to long-term situations involving HD, Alzheimer's disease, and other afflictions.

Overlooked and undervalued

Until my mother went into a nursing home in the final months of her life, my father cared for my mother's daily needs with the assistance of a professional caregiver who visited their home a few hours each week. He helped her in the bathroom, fed her, and pushed her wheelchair.

She was the love of his life. He was stubborn about accepting more help at home and getting her physical therapy, but each day he climbed with her into the HD trenches.

Not once did I hear him complain. Maybe he should have!

In our celebritocracy, such dedication goes unrecognized. Each year family caregivers are estimated to provide the equivalent of nearly half a trillion dollars in unpaid care.

In America, care and caregiving are “overlooked and undervalued,” writes Zachary White, Ph.D., the author of the blog *The Unprepared Caregiver*.

Unlike highly valued, professional jobs, informal caregiving isn't considered a career.

“Parents and relatives and friends won't be able to brag about your experiences.” Dr. White writes. “There are no ‘schools’ of informal caregiving – no Harvard or Stanford to use as a guiding goal from which others can respect and admire. Others may speak highly of your role and your efforts, but it begins and ends there.”

While taking care of loved ones, members of the HD and other neurological disease communities have long advocated for better caregiver assistance and nursing home care – including disease-specific instruction for health aides. These will remain daunting challenges for the foreseeable future.

Preemptive caregiving

I believe that Regina's devotion to me and our family is a big reason why I've passed my mother's age of HD onset. She helps provide for the family by working as a full-time elementary school teacher; she sees to it that Bianca and I eat healthily; and she supports my HD advocacy.

She has done a lot of preemptive caregiving.

Caring for Regina during her recovery and remembering my mother's struggles with Huntington's have led me to reflect on my future caregiving needs.

As I race against the genetic clock and await the development of treatments for this incurable disorder and a health care system more responsive to those with brain diseases, I want to avoid becoming a burden on my family.

By maintaining good health in the present, I can perhaps reduce that future burden.

However, I know that, for each HD family, this is uncharted territory. We can forge ahead by caring for our our family members – and for the larger community.

Posted by Gene Veritas at 7:23 PM



Labels: brain , caregivers , caregiving , emotions , genetic clock , Huntington's disease , juvenile Huntington's , mother , neurological , nursing home , onset , preemptive caregiving , wheelchair

1 comment:

Anonymous said...

<http://www.e-digitaleditions.com/i/637578-vol-13-l-winter-2016/9?>

Above is a link to a "Meet the Company" Q&A Session from the Winter 2016 Edition of HD Insights.

The Q&A was conducted w/ Ionis Pharmaceuticals' staff on the Ionis-HTTRx Phase I/IIa trial in early manifest HD patients.

7:18 AM, February 23, 2016

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