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Bidding farewell to my 'mind coach,' a major ally in my fight to avoid 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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SATURDAY, SEPTEMBER 18, 2021

Bidding farewell to my 'mind coach,' a major ally in my fight to avoid Huntington's disease

In December, my psychotherapist will retire, ending for me a professional relationship of 24 years that became the most personal of bonds and an emotional bulwark in my fight to delay – and prepare for – the inevitable onset of Huntington's disease.

I had consulted therapists in my twenties and early thirties for non-HD-related matters. However, after my mother's diagnosis with HD in 1995 and her inexorable physical and mental decline, I spiraled downward into clinical depression and anxiety. I needed more profound, long-term psychological support.

I contacted the local psychoanalytic society, which, after an intake interview, put me in touch with a psychoanalyst who best matched my needs and goals. I was fortunate that she proved to be a good fit. I recommend a proactive attitude about therapy, with a willingness to ask questions, and, if necessary, switching to another analyst or therapist.

For me, so began a journey of seeking greater personal and social enrichment. HD researchers and physicians have long encouraged a healthy lifestyle, although [no one has found evidence](#) to prove its effect. However, as discussed below, scientists are seeking ways to use HD-affected individuals' sense of meaning and purpose as a possible path to alleviating symptoms.

My psychotherapist has certainly helped me build meaning and purpose not just in my fight against HD, but in life in general.

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As the format of my therapy went from classic psychoanalysis (multiple sessions per week lying on a couch) to a face-to-face encounter on a weekly, bi-weekly, and then monthly basis, I have referred to my therapist in different ways.

“My therapist is like a personal trainer,” I [wrote in 2009](#). “She’s my mind coach. She helps me keep my mind working at its best to meet the challenges of living at risk for HD, just as a personal trainer or coach helps a professional athlete keep his body in top shape.”



Gene Veritas, aka Kenneth P. Serbin (photo by Yi Sun, Ph.D.)

Psychoanalysis: unleashing personal growth

Founded by the Viennese doctor [Sigmund Freud](#) in the early 1900s, psychoanalysis became the basis for modern talk therapies, in which the patient shares inner thoughts with the analyst, or therapist.

Although in the United States in the latter 20th century psychoanalysis was reduced to a small branch of the burgeoning psychological profession, it remained important in parts of Latin America, including Brazil, [my second home](#). I researched the history of the Roman Catholic Church in Brazil for my Ph.D. dissertation, published as [Needs of the Heart](#) in 2006.

From the 1960s to 1980s, the Brazilian Church became the world's most progressive. In *Needs of the Heart*, I wrote that in this period Brazil helped give birth to the important and controversial liberation theology, "but also to liberation psychology, whose implications for the Church were even more revolutionary than the new theology."

"Liberation psychology had a dual significance," I asserted, referring to psychology in the broad sense, including psychoanalysis and many other approaches. "It could free people not only from poverty of spirit and mind but also from the repressive structures of Catholicism." Liberation psychology sought to release people from such beliefs as the need to repress sexuality and unquestioningly accept religious authority. This history resonated deeply with my Catholic upbringing.

Igor Caruso, a Viennese Russian Orthodox analyst and an inspiration for Brazil's pioneers of liberation psychology, viewed psychoanalysis as ultimately an encounter of love "between two unique and equally valuable personalities." As I wrote, he believed that without love, there was no cure.

One leading priest-analyst in Brazil described psychoanalysis as a "special grace received from God" because of the profound self-discovery and personal growth it unleashed in people.

Although psychoanalysis in the U.S. fell behind other areas of psychology and medicine in terms of scientific innovation, it has, with the rise of neuroscience and molecular biology, experienced a renaissance. Using brain imaging, researchers have been exploring how different types of psychotherapy, including psychoanalysis, affect brain structure. (For details, see [Nobel Prize laureate](#) and brain scientist Dr. Eric Kandel's *In Search of Memory*.)

Also, as I experienced, psychoanalysis could be aided with psychiatric medications.

About a year after learning about my mother's HD diagnosis, during a year-long research stay in Brazil, I did therapy with a

local analyst for several months. She urged me to continue analysis in the U.S. after my return in mid-1997.

Sharing the trials and triumphs of the HD cause

I, too, became liberated by psychoanalysis. As is often the case, the process took years.

In December 1997, I met my analyst for the first time. After a few preliminary weekly conversations, I lay on my therapist's couch four times weekly, for 45 minutes, over about five years.

I always paid out-of-pocket: my insurance did not cover psychoanalysis. Fortunately, the psychoanalytic society sought to help people of all income levels. In retrospect, paying privately gave me a greater sense of security about confidentiality, because (in one of those terrible ironies of the U.S. health system!) I was deliberately keeping my HD status from my health plan, for fear of discrimination and losing my health coverage, until fully going public in 2012 ([click here](#) to read more).

As we talked, my analyst took copious notes on my thoughts and asked questions. I spoke mainly about my fears, feelings, and past, especially with regard to my relationship to my family, in particular my mother, who was slowly dying of Huntington's.

My therapist listened intently and compassionately to my many struggles with HD and, more than anyone else, came to know how my fear of the disease – along with other factors – hindered clear thinking and the ability to enjoy life. She also shared my pride and joy in the many fundraising and awareness-building triumphs I achieved with others for the local chapter of the [Huntington's Disease Society of America](#) (HDSA).

My psychotherapist helped me cope with the impact of my positive test for the HD mutation in 1999, my daughter's negative test in the womb in 2000, and my mother's death from HD in 2006.

Descending into the bedrock

By early 2003, we had reached a point in the analysis where I needed – and wanted – to descend into what I called the “bedrock,” the deepest, most difficult feelings, fears, and memories, which are the hardest to access and confront. Rooted in childhood and adolescence, they long preceded my family’s struggles with HD. However, I seemed incapable of entering the bedrock. Part of my mind resisted both my therapist, and myself, preventing me from being completely honest with myself and gaining more self-understanding.

My therapist gently pushed me to consider psychiatric medication to overcome that resistance.

Holding a Ph.D., but not an M.D., my therapist could not prescribe medicines, leading me to work with psychiatrists at my health plan.

That process proved difficult and frustrating; rather than specify my true concerns to these doctors, who knew nothing of my HD status, I had to speak in generalities.

Finding a winning combination

In addition, finding the right medication and the right dosage required years of trial and error. My first attempt, with [Zoloft](#) (sertraline), nearly proved disastrous: while driving my wife and daughter, I blanked out and ran the car onto the curb. Luckily, no one was injured. I immediately quit the medication.

Next, [Prozac](#) (fluoxetine) left me disoriented and extremely drowsy, so I was switched to [Zyprexa](#) (olanzapine). My mother was also taking this drug for her HD symptoms as an alternative to [Haldol](#). Haldol was one of the standard prescriptions for HD but, we heard from the HD community, not recommended in many cases.

With worsening clinical depression and especially anxiety after my mother’s death in 2006, and working with a highly sympathetic psychiatrist (but who still did not know my risk for HD), I found a

winning combination of [escitalopram](#) and [risperidone](#) for the respective conditions.

Since the late 1990s, I had also taken [trazodone](#) for sleep but quit in 2016 because I had improved on that front considerably. I have also wanted to avoid overloading my system with medications.

In contrast with Zoloft and Prozac, escitalopram and risperidone apparently did not cause any unpleasant side effects, although, according to my doctors, I have taken these last two drugs at very low doses. A general caution I heard from doctors: certain antidepressants can [negatively impact sexual function](#).

Taking these medications was a huge step, because growing up I learned that psychological counseling and especially anything psychiatric were taboo and seen as shameful by many in my extended family.

Fear of HD diminished dramatically

In my late 40s, this successful treatment of escitalopram and risperidone relieved me of depression and greatly reduced my anxiety. In tandem with my therapy, these drugs finally helped me psychologically to feel as well as I ever had in my adult life. I have now taken them at the same dosage for more than a decade, and will do so for the foreseeable future.

Entering the bedrock, I continued to gain new insights with my therapist. The fear of unconditionally trusting her disappeared. I was able to comprehend my psyche. I became more perceptive and more self-aware – and also more accepting of others and more loving towards my family.

My fear of HD diminished dramatically – even though I knew that each day brought me closer to the likely onset.

I have the normal ups and downs we all have, but the medications continue to help keep me stable.

The benefits of stability

In 2011, my therapist helped me prepare for, and then marveled at, a major achievement in my HD advocacy, the first major step outside the “terrible and lonely HD closet”: my [keynote speech](#) at the Sixth Annual HD Therapeutics Conference, sponsored by [CHDI Foundation, Inc.](#), the nonprofit virtual biotech firm that is the largest private funder of efforts to develop treatments.

My therapist provided support for another milestone, and the beginning of the fully public phase of my advocacy: the publication of my article [“Racing Against the Genetic Clock”](#) in *The Chronicle of Higher Education* in 2012.

Psychological stability enabled me to work ever more effectively as an advocate and to concentrate on activities such as exercise that have bolstered my health. By then, I had also come off the couch, and our meetings became less frequent.

My therapist also became a regular reader of this blog. In some sessions, we have discussed concerns I have expressed in articles. On other occasions, therapy has helped suggest blog topics.

My therapist has been a true friend and partner in the fight against HD!

A broad strategy for avoiding symptoms

In recent years, as I have proceeded into my sixties, I have reflected on how I have so far avoided HD symptoms. On September 17, during my annual neurological checkup, the doctor found no signs of HD. My mother became symptomatic in her late forties and died at age 68. ([Click here](#) to read more.)

Psychotherapy forms part of a broad range of interrelated strategies for keeping healthy, including physical and mental exercise, blogging on HD, and taking supplements, some of which were ultimately proved ineffective. I also eat a healthy diet, and I meditate and practice spirituality. I have the benefit of a stable, solid-paying job and a close relationship with my wife and daughter.

As psychotherapy has helped enrich my life, it has also given me a greater overall sense of meaning and purpose.

Researchers are carefully studying these factors as a way to alleviate symptoms.

Meaning and purpose are key

In July, a team of twelve researchers published "[Meaning and purpose in Huntington's disease](#): a longitudinal study of its impact on quality of life," in *Annals of Clinical and Translational Neurology*, a journal of the [American Neurological Association](#).

The researchers studied 322 HD-affected individuals: 50 just starting to experience symptoms, 171 with early-stage disease, and 101 with late-stage disease. The participants did both an in-person assessment and an online survey. Data were collected between 2012 and 2016.

The results of the study demonstrated that "higher" meaning and purpose were "positively associated" with "positive affect [mood] and well-being," the researchers stated.

Meaning and purpose also were associated with "decreased depression, anxiety, anger, emotional/behavioral disruptions, and cognitive decline at 12 and 24 months across all disease stages," they wrote.

More research needed

The article pointed out the study's limitations: correlation does not necessarily mean causation.

Thus, the researchers recognized the need to verify their findings with "additional instrumentation" to measure the connection between meaning and purpose and the patient-reported data. The study also did not account for possible bias from people on "psychoactive medications."

Nevertheless, the researchers described the study as a “compelling first step” toward understanding the primary mechanism behind meaning and purpose – and how they might improve quality of life in HD-affected individuals.

Finding ways to help patients

The researchers concluded that their findings “parallel” those seen in those affected by cancer and might help point the way to “palliative HD interventions,” approaches that might relieve symptoms without removing the root cause.

They also pointed to the value of psychotherapy. They cited articles from studies of cancer patients and other conditions focusing on psychotherapy and other palliative measures such as spirituality.

Critically, a sense of meaning and purpose “may serve as a resiliency factor for suicide in people with the HD gene in that it can impact factors associated with suicidal ideation (e.g., depression, anxiety) as well as suicidal behaviors (e.g., impulsivity and anger).”

As the article pointed out, and as is well-known in the HD community, “suicide is a leading cause of death.”

Nostalgia, and looking ahead

As I read the journal article, I recalled my own fantasies about suicide in the first few years after my mother’s diagnosis and as I worried whether I had inherited the mutation.

The birth of our daughter in 2000 gave me immense meaning and purpose. I stopped thinking about suicide as a way to escape HD. My fight against HD became not only advocacy for the cure, but a personal quest to maintain stable health so that I could see my daughter grow up.

My mind coach has been an invaluable companion in this journey.

As we have our final sessions, I will become deeply sad. It feels like a lifelong friend moving to another city, with little chance of a visit.

My therapist and I have discussed the pain of separation. As usual, she will be helping me to remain stable and find a good path forward.

With nostalgia, we have also discussed the tremendous progress I have made, including the highlights of my HD advocacy.

In July, I began meeting occasionally with another therapist, so that I have psychological support beyond my mind coach's retirement.

I am looking forward to discovering another ally in the fight against Huntington's.

Posted by [Gene Veritas](#) at [4:27 PM](#)      

Labels: [anxiety](#) , [depression](#) , [diagnosis](#) , [escitalopram](#) , [Huntington's disease](#) , [liberation psychology](#) , [meaning and purpose](#) , [psychiatric](#) , [psychoanalysis](#) , [psychological counseling](#) , [psychotherapist](#) , [risperidone](#) , [symptoms](#)

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