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Proof of heaven? My ongoing search for the meaning of Huntington's disease in life and death

Kenneth P. Serbin
University of San Diego

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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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WEDNESDAY, FEBRUARY 05, 2014

Proof of heaven? My ongoing search for the meaning of Huntington's disease in life and death

The knowledge that I carry the Huntington's disease genetic mutation and will inevitably develop devastating, ultimately deadly symptoms has led me to intensify my search for the meaning of life, especially after the death of my mother from HD eight years ago this month.

As a historian tracking neuroscience developments and the quest for an HD treatment, I am also deeply interested in the nature of the mind and consciousness. This growing field of inquiry is full of new insights and challenges.

In 2010, I wrote an article titled "[God, Huntington's disease, and the meaning of life,](#)" in which I explored human evolution as the cause of the HD mutation but also the impetus towards greater consciousness of our species, a vast network of thinking beings.

HD may serve "a purpose as of yet undiscovered," I wrote. "HD people have a huge cross to carry, but they should see their lives as part of the evolutionary surge towards a better life for all."

I saw that thought partially confirmed in Brazil last September at the sixth World Congress on Huntington's Disease, where renowned HD researcher Dr. Elena Cattaneo noted that the normal huntingtin gene, present in all humans and many other species, has a "social function, because it brings cells together.... Huntingtin is a *good* gene."

Dr. Cattaneo offered an insight from a study of 300 normal brains: the greater the expansion of the huntingtin gene's DNA (HD happens when the expansion is too great), the greater the amount of gray matter, or neurons, and therefore the larger and potentially more complex the circuitry of those brains. ([Click here](#) to watch Dr. Cattaneo's presentation.)

Thus, because brain enlargement has played a key role in human evolution, the huntingtin gene might have had a part in the creation of human intelligence.

In my 2010 article, I also explored the oft-denied nexus between faith and science and the centrality of consciousness in the human experience by analyzing the life and writings of the so-called Catholic Darwin, the Jesuit paleontologist-priest Pierre Teilhard de Chardin.

In other articles, I have described how faith has given me the courage to confront the many challenges posed by HD.

An intriguing title

A large part of my focus on spirituality involves its effectiveness as a coping mechanism.

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](#)

Last year, I augmented my morning meditation with a reading from *Living Faith: Daily Catholic Devotions*. Based on Biblical passages, the practical spiritual advice offered in this booklet helps me focus on meeting life's challenges and becoming a better person.

Like many believers, however, I haven't thought much about heaven and the afterlife – until last month a book title flashed across my TV screen and intrigued me with its seemingly incongruous combination of two words: "heaven" and "neurosurgeon."

I felt moved to almost immediately download onto my Kindle Dr. Eben Alexander III's account of his near-death experience (NDE) and purported encounter with God, the bestseller *Proof of Heaven: A Neurosurgeon's Journey into the Afterlife*.

I knew almost nothing about NDEs other than what I glimpsed on TV programs about them over the years, but now that a neurosurgeon had experienced one and written about it, I felt the need to take the matter more seriously.

Because of my HD advocacy, I have delved into the world of neuroscience research, where scientists seek to explain phenomena such as NDEs purely in terms of the brain. Many scientists reject the supernatural, although notable exceptions do exist such as [Dr. Francis Collins](#), the head of the National Institutes of Health and one of the individuals responsible for the discovery of the huntingtin gene.

Quite frankly, thanks in part to the intellectual rigor of both believing and non-believing scientists as well as my own experience as an academic and historian, I have also learned to keep an open mind with regard to practically any question or mystery.

As an HD advocate, I was also anxious to learn what Dr. Alexander might have to say about the brain and disease.

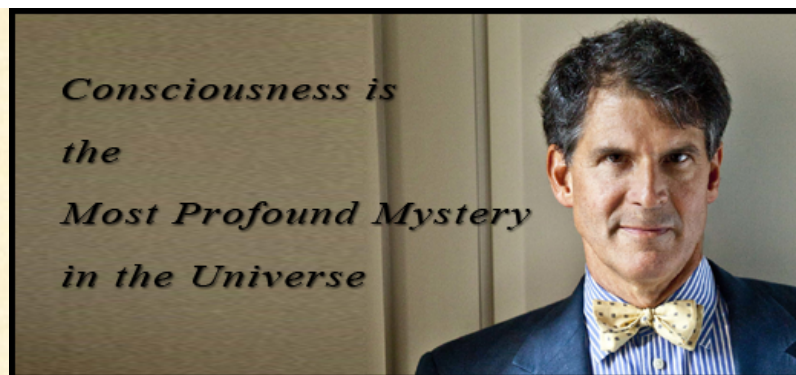
I had another, very important reason to read *Proof of Heaven*. Seeing a title that hinted at the existence of scientific proof for heaven fulfilled a growing desire for hope stirred in me by the approach of old age and especially the inevitable onset of HD.

Discovering the soul

According to Dr. Alexander, he had lain in a coma for a week, his brain under a severe attack from an untreatable, unique form of meningitis. He should have died, but, in the words of one of the attending physicians cited in the book, staged a miraculous recovery.

Dr. Alexander claims that, during his time in coma, he was transported to another realm, where he encountered a kind of guardian angel and learned truths about the universe and the overwhelming power of love. He explains that he found many of those truths extremely difficult to describe in the language of earthly existence.

Once a typical, scientifically oriented skeptic about the spiritual dimension, Alexander became a man of deep faith committed to revealing the significance of NDEs.



Dr. Eben Alexander III (photo from author's website)

“Science – the science to which I’ve devoted so much of my life – doesn’t contradict what I learned up there,” Dr. Alexander writes. “But far, far too many people believe it does, because certain members of the scientific community, who are pledged to the materialist worldview, have insisted again and again that science and spirituality cannot coexist. They are mistaken....”

“In fact, I feel confident in saying that, while I didn’t even know the term at the time, while in the Gateway and in the Core (heaven), I was actually ‘doing science.’ Science that relied on the truest and most sophisticated tool for scientific research that we possess: Consciousness itself.”

According to Dr. Alexander, during his NDE he had discovered the existence of his own soul – a form of consciousness outside of the body and the brain-generated mind.

He summed up the message from heaven: “Love is, without a doubt, the basis of everything. Not some abstract, hard-to-fathom kind of love but the day-to-day kind that everyone knows—the kind of love we feel when we look at our spouse and our children, or even our animals. In its purest and most powerful form, this love is not jealous or selfish, but unconditional.”

A convincing yet disappointing story

As I read Dr. Alexander’s account and gained hope for the future, I became ecstatic. *Finally*, I thought, *I can truly look forward to the afterlife! I will continue to fight for the cure of HD, but I don’t have to worry about dying! Finally, someone has nailed down proof of heaven!*

As I read the book, however, I also felt disappointed at how little Dr. Alexander could say about God and heaven, because of the admitted human limitations in describing the experience.

At about 200 pages, the book also struck me as very short for a topic of the utmost importance.

In addition, his description of the cosmos seemed to echo scientific hypotheses put forth on earth. Of course, in reality scientific ideas and divine revelation about the cosmos should coincide. However, I wondered whether his perception was a true insight from God or simply a projection of his professed love for physics and cosmology.

Despite these criticisms, I found the book highly convincing.

A hallucination?

But then I thought some more and dug more deeply.

Jesus was the son of a carpenter. Eben Alexander III is a neurosurgeon who taught many years at Harvard University.

Here on earth, Dr. Alexander's status *validates* the idea of the NDE. People crave such validation when considering an idea – or buying a book – even though the idea could stand on its own when carefully considered.

Wanting to see what others thought of Dr. Alexander's book, I discovered the expected response from some in the scientific community. An article in *Scientific American*, for instance, concluded that Dr. Alexander's experience was "proof of hallucination, not heaven."

Esquire magazine contributing editor Luke Dittrich wrote a long, unflattering expose of Dr. Alexander's departure from Harvard, his status as a defendant in a series of malpractice lawsuits, the suspension of his operating privileges, publisher Simon & Schuster's manipulation of and shortening of the original manuscript, and inaccuracies in *Proof of Heaven*. Dittrich describes Dr. Alexander as a self-proclaimed "prophet," a man in reality seeking in the time-honored American tradition to remake himself in the wake of legal and professional difficulties.

Dr. Alexander's website contains a rebuttal to the piece by *Esquire*, which it accuses of "journalistic malpractice."

In *Proof of Heaven*, Dr. Alexander states that material success became unimportant to him after his glimpse of the afterlife. Aside from some bracelets for sale with half the proceeds intended for charity, I could find nothing about the destination of the presumably millions of dollars in royalties Dr. Alexander has earned from sales estimated in mid-2013 at nearly two million copies.

For me, the jury is still out on Dr. Alexander's story.

The larger context

Ultimately, only God would know exactly what happened to Dr. Alexander during his near-death experience.

For me, the book is important because it contributes to the effort to create a synthesis of faith and science.

Proof of Heaven also rekindled my interest in the afterlife and introduced me to the seriousness and breadth of NDEs. Whether one believes in the soul or not, NDEs can and should be studied in the larger context of understanding how the brain and consciousness work.

A seemingly infinite number of mysteries about our existence remain to be solved.

Seeing patients as persons

While I can't judge the veracity of Dr. Alexander's NDE, reading his book made me reflect on my mother's final days in January and February 2006. *Proof of Heaven* has also helped me come to a fuller and more compassionate understanding of Huntington's disease patients.

My mother struggled with HD for nearly two decades.

In the HD community, because we need to build awareness, we are so used to emphasizing the devastation of the disease. The devastation is real. But there is more to the person. Some readers of this blog have reminded me that I have not recognized this.

I regret not having the emotional strength and presence of mind to have seen my mother more as a person, *with a consciousness and perhaps even*

a soul, and less as a mind and body racked by the symptoms of Huntington's. Because I had tested positive for the mutation, "my fear of HD kept me from sitting down with her and attempting to converse," I wrote in a blog entry titled "[Saying good-bye to Mom.](#)"

My mother's astonishing gesture

Only near the end of her life did I really perceive that a powerful life force continued in my mother.

The first evidence of this came in a phone call from my California home to my mom's nursing home in suburban Cleveland. I wrote: "The nurse bluntly revealed an emotional bombshell: Mom had said that she was 'not afraid to die.'"

I was struck by that revelation, because for years she had not spoken in any intelligent manner.

Looking back on our good-bye, I now see more clearly the increased presence of her consciousness and the degree of her "cogency" (Dr. Alexander's word to describe another situation) as she prepared to die. Demented elderly people on their deathbed sometimes achieve an "astonishing clarity of mind" known as "terminal lucidity," he notes.

I wrote: We then wheeled Mom to a reception room with more comfortable furniture. There we took some pictures.

Then I asked my sister and father to leave the room briefly so that I could say my final farewell to Mom.

I told Mom that I was saying goodbye and that I might not see her again. I told her what an excellent mother she had been, and I apologized for all the times that I had not been the best of sons.

I looked her in the eyes.

I hugged and kissed her.

I put her hand on top of mine on top of the tray that was part of her special chair.

I told her I loved her. She said she loved me too.

In the past couple days Mom had not moved her hands at all. When we asked her to point out things, she had been unresponsive. But then, inexplicably, Mom started to move her left hand upwards. Slowly it moved until it touched my face.

I took her hand and pressed it against my face.

Miraculously we had touched each other's hearts.

I felt a warm glow of love and relief.

A wonderful gift

Wanting to know a Huntington's disease specialist's assessment of my mother's cogency, I asked Dr. Martha Nance, a neurologist and the director of the Huntington's Disease Society of America Center of Excellence at Hennepin County Medical Center in Minneapolis, to comment via e-mail.

"I don't know what to say about consciousness independent of mind and body," Dr. Nance responded. "My work and personal worlds do not operate on that plane, if there is such a plane of existence."

However, Dr. Nance has heard extraordinary stories about and from patients suffering from neurological disorders, like the woman dying from progressive supranuclear palsy who on her last day had a vodka martini with her husband and their best friend from college days.









Dr. Martha Nance (photo from HDSA website)

As Dr. Nance told it, the patient “raised her hand that hadn’t moved in a week, and took her own glass. She then raised the glass up in the air – a toast to life – and put it to her lips. She died quietly that night.”

What causes these moments of lucidity? Science hasn’t yet found the answer, Dr. Nance replied.

“If you play your cards right, this kind of thing can and does happen,” Dr. Nance wrote. “The point is, if you acknowledge the coming of death, perhaps even embrace it, that it can be at least peaceful, and sometimes beautiful. And strange moments of lucidity or awareness shortly before the final moment do seem to happen (sometimes, not always) – and are a wonderful gift to the family when they do.”

Posted by [Gene Veritas](#) at 12:59 PM      

Labels: [afterlife](#) , [Catholic](#) , [consciousness](#) , [death](#) , [Eben Alexander](#) , [God](#) , [hallucination](#) , [heaven](#) , [Huntington's disease](#) , [mother](#) , [near-death experience](#) , [onset](#) , [patient](#) , [soul](#) , [symptoms](#) , [Teilhard](#) , [treatment](#)

5 comments:

 **Anonymous said...**

Dr. Alexander definitely got at least 2 points right: Love is the ultimate thing (the Holy Bible defines God as love, and Jesus calls us to love God first and foremost but to also love others equally well), and science does not have to contradict our

belief. In fact, often science confirms facts from the Bible. It's those theories taken as fact that often create debate and divide. Having been a former evolutionist, I'm speaking from both sides of that debate. The more I studied and learned, the more I became convinced that Creation is how we came into being, and that God created each human being uniquely in His image with a purpose of holding a relationship with Him. That relationship is not based on our own efforts, for we are all sinners and can't do anything to earn God's favor, but it's based on what we do with Jesus as our only Mediator between God and ourselves. And yes, that includes, and hinges, our afterlife. Keep searching Gene, for the Kingdom of God is nigh.

8:59 PM, February 07, 2014

⌘ **Anonymous said...**

My mother fought this disease for over 30 years. I had no idea what was causing us to fight. I was 13 when she first became sick. She was a perfect and very enjoyable parent before this. She admired the Kennedy lifestyle and tried to give her three boisterous children something similar. This included lively nightly debates at the dinner table. I participated in every activity that made me happy. She suddenly changed. By the time I was fifteen she was screaming and throwing things at us with little or no provocation. I thought I had failed as her child. Flash forward in time and my beloved mother was diagnosed with everything but was most obvious. She had Huntington's Disease. When I found the correct diagnosis online she was in the Intensive Care Unit. Her Grandfather was a prominent minister in New York City and her father was an Irish Catholic Jesuit Priest who left the priesthood. Her journey though the last year of life was filled with head stroking, hand holding and prayers from her children. We told her how much we loved her and that Jesus would take her home. I apologized extensively for any harsh moments we had. At the end of life, as described above she began to rally. I said "Mommy, I love you!". She tried to reach for my hand and said in a HD slurred voice "I love you too." I am so grateful to God for this and her lucidity on the last day of her life. We watched the eclipse together out the window cuddling each other. I kept talking about God and Jesus and going home. I can say that for those facing this disease, putting a human and spiritual face on the difficult journey is so very necessary.

11:58 PM, February 07, 2014



⌘ **Becky said...**

I haven't read this book this book yet, but have read a couple of good books on NDE's. My latest book, "Held By The Hand Of God: Why Am I Alive" by Joe Laws <http://heldbythehandofgod.com/> was amazing! One thing I got from it that I haven't gotten from any of the other NDE books is

that that by doing good in life, we will be rewarded in our afterlife.

3:39 PM, March 17, 2014



Unknown said...

What a horrible disease, yet such an incredible story from Dr. Alexander. Thank you for sharing this. It has sure been an eye opener for me! Becky - your book looks very interesting. I will go take a look at that now :-).

11:04 AM, March 18, 2014



Becky said...

Thanks Ashley! I hope you enjoy it as much as I did!

11:31 AM, March 18, 2014

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