

Dementia: The Paralyzing Enigma of Our Generation

By Stephen Sarsfield Bowman

Dedication

**To Maria, my One Love
You believed in me, my vision of care, and this book,
More than I,
Thank God**

**Very truly I tell you,
When you were younger,
You dressed yourself
And walked wherever you wanted,
But when you are old,
You will stretch out your hands,
And someone else
Will dress you, and carry you to places
You do not want
To go.**

John 21:18

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Preface

Reflections and the Peregrine Way

The specter of Dementia has been haunting us in silent desperation for decades and this stalking Golem continues right up to this very moment. Everywhere I go, when people learn of my avocation, they share the thunder that has struck their family. “My father had Alzheimer’s’ for seven years and we knew nothing...” and then a bewildered blank stare. The crisis is everywhere. It seems too many of us and our loved ones, are destined to suffer a purgatory of our own making, in a world without end.

Many years ago the broken kaleidoscope of dementia came into slight clarity for me when I was giving a lecture in Atlanta on World War II at one of our Memory Care

communities. I brought up a slide of Adolf Hitler, and instantly Renee, one of our residents blurted out” he killed little children in a basement”. I asked her what she meant, but she only repeated her charge, staring in anger at the photograph. Renee had been a little girl herself during the war and lived in Belgium.

I thought about what she had said and remembered that Joseph Goebbels had killed his own children in Hitler’s bunker at the close of the war; first using a heavy dose of morphine, then cyanide. Some reports tell us that at the end they were beaten to death when resisting the cyanide. It was a bloody deadly scene.

As I looked at Renee, I marveled. Of all of her memories of the war, the capitulation of Belgium and occupation, the death of family friends through bombing raids, and the Holocaust, what she remembered most vividly seventy years later, was the murder of children like herself. Clearly, beyond her other powerful memories, and what she learned as an adult, what dominated her reaction to a picture of Hitler, was to be found in her long term childhood memories, through her empathy for other children and the horror that was evoked in her young soul.

What could this primacy of long term memory tell us about her disease, and how should she be cared for? I started to think.

I came to senior housing and innovative models of care quite by accident. Seven years after law school, I started a health care real estate company and three years later, I was joined by my lifelong family friend, Mark Farchione, also a lawyer. At the time, my interest in senior housing was narrow and self-serving. I wanted to follow in the stream of the Baby Boomers and their parents. Many successful businesses, or at least lifelong employment, had been secured by people following the wealth left behind in the flotsam and jetsam of this generation: Post war suburban housing, baby food and diapers, rock and roll, the internet, and now retirement stock portfolios, and Viagra.

It soon became apparent however, that developing buildings alone was not truly serving the needs of our aging seniors. We needed to consider what was happening inside these buildings; we needed to address our programing, our vision of care. We found our models of care for our seniors with dementia particularly perplexing and unacceptable.

I care about ideas, policy, and am a lifelong learner. And what could be more compelling than the challenges of our dementia epidemic: philosophically, programmatically, and spiritually. So in some ways, my career in long term care forced a collision between my prosaic business ambitions, and

my interest in ideas all toward the end of our too rarely considered aging predicament. To this day, I have been very grateful for this convergence. I have been able to support my family, essentially by developing bricks and mortar, but more importantly, dealing daily with life and death, time, and the mission of the soul. This has been a very humbling gift and challenge.

Over time, through trial and error, and listening to the insights of our experienced aids, we came to a vision of care we call the Peregrine Way. Curiously, as it turns out, our approach is largely 180 degrees different from that of the long term care industry, in the way we treat memory, stimulation, and families. This evolving vision is incomplete and still in search of better answers. But it is a beginning in a race that our society should have joined in earnest, many years ago.

Our company, Peregrine Senior Living develops and operates assisted living communities around the country, and our focus and experience deals with congregate care communities. But of course if our ideas ring true regarding the Peregrine Way, they would be helpful at home, as well as in an assisted living community.

What was in the 1970's troubling adumbrations and forewarnings of a storm to come, has today become a deluge that few of us are prepared to weather, as the water rushes over our afflicted families. It seems we have more in common with Jonah than Noah. Some may read these words as overly

dramatic, but the cost in humanity, public and private finances, and spiritual abnegation, our crisis is staggering and rarely considered until the tragedy is our own.

Up until now, our society has only tried to stare down the disease, rather than engage aggressively and creatively with a vision that goes to the heart of our humanity. Our world in twenty years will be unrecognizable from what we know today, and for many of us a horror. Today dementia already out paces heart disease and cancer in costs, and soon it will cripple our spiritual lives as we watch our loved ones die slowly and hopelessly over many years. It is not just a hardship as to a loss of life, it is a spiritual challenge as we are forced to linger with the slow careening deaths of loved ones that have lost their jib, main sail and rudder. We have a catastrophe my friends, and as a culture we are suffering in silence and hesitation: an inexplicable paralysis. We must awake and engage this disease. Our somnolence to taking a profound toll on our aspirations for ourselves and our beloved.

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