

Hope for ALZHEIMER'S

Hugh Gilbert



The Long Goodbye

"The Long Goodbye" is what Alzheimer's disease is now known as internationally. Only those families who are currently living this nightmare with a loved one, or who have gone through it in the past can even begin to comprehend the truly terrifying meaning of this name and the crushing stress and suffering involved for all of the family as the nightmare unfolds. It is currently a journey without any real hope of reprieve in any form—until this story.

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Hugh Gilbert



The Larry Czerwonka Company, LLC
Hilo, Hawai'i

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*In Loving Memory of my father,
Leo Howard Gilbert 1920 to 2011
an Officer and a Gentleman.*



Books by Hugh Gilbert

THE EARLY-AGING WORK FORCE

FREE THE UNICORN

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This is a story of miracles and celebration, not just for my father and his family, but potentially for millions of other Alzheimer's sufferers and their families. The struggle faced by families in coming to terms with the stark reality of the effect of Alzheimer's and the numbing ripple effects which resonate in all directions is an area which has not been adequately addressed on any level. There is little or no professional help available to counsel family members through this protracted nightmare. For the most part we are left to flounder along, with each one of us dealing with it from his or her own personal perspective. It is an unsupportive and helpless environment with no hope for anything other than the certainty of a protracted physically, emotionally and often financially devastating terminal journey. This has to change in the future. However, in my efforts to come to terms with all of this I suddenly became aware of a very bright ray of hope for a potential cure and I was met with resistance on every level as I tried to get my father the chance he so desperately needed. How can a potential cure be simple and easily implemented? Your understandable current doubt and skepticism will gradually dissolve and you will be amazed at the potential of it all. 5

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The story you are about to read of the last two and a half years of my father's life has apparently become a glowing beacon for many people.

I have been told it has been the focus of study groups internationally and is being quoted by families in Hawai'i, North America, South America and Europe as they fight for their loved ones facing similar circumstances. I trust it proves a source of inspiration and understanding for you also. 7

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Preface

“The Long Goodbye” is what Alzheimer’s disease is now known as internationally. Only those families who are currently living this nightmare with a loved one, or who have gone through it in the past can even begin to comprehend the truly terrifying meaning of this name and the crushing stress and suffering involved for all of the family as the nightmare unfolds. To give some basic perspectives as to the impact this terrible illness has, with as yet no cure or hope of slowing it’s progress (until this book) even vaguely in sight, I give you a small sampling of financial ramifications to society.

1. According to the National Audit Office in 2007: “Dementia costs the U.K. economy 20 BILLION pounds per year (\$38 Billion Dollars). The costs per person are higher than for all other mental health conditions.”
2. According to the U.K. Alzheimer’s Society in 2009 in a document called “Counting the Cost”; “Up to 1 in 4 hospital beds at any one time is occupied by a person over the age of 65 who has dementia.”
3. According to the U.K. Department of Health in 2009: “By 2039 there will be 1,400,000 people with dementia in the U.K.”

We can only shudder at the thought of what those numbers will be in North America and other Continents.

In this book I will offer you some simple, easily defensible strategies, with early intervention being a prime, but not total focus, which, if implemented, could save a minimum of 5% of these costs, the equivalent of a BILLION pounds, or 1.6 BILLION dollars per annum.

Far more importantly and joyfully, we can quantifiably delay the early progression of the condition; improve the quality of life of those suffering and provide their families with at the least, more quality time with their loved ones or, at best, stunning, heart-warming and sustainable improvements in physical capabilities and communication!

The strategies are based on my experiences when dealing with this progressive illness in my father, Leo Gilbert, and are not born of conjecture of

any kind. My hope is that many will gain hope and take action in implementing the tools offered, and that enough of a groundswell of public demand will get the attention of the medical community and full University Research Studies will be implemented to prove the validity of my findings. I feel it is worth reemphasising here that the simple strategies that worked for my Dad will have maximum benefit if applied to patients MUCH earlier in the onset of the illness. Time is of the essence.

The first few chapters are difficult to write and possibly to read, however it is vital to have them as it clearly describes the slippery slope of bewilderment and increasing devastation that hundreds of thousands of families have faced and are facing today. Once we get to the point where there seems to be no hope left is when the story shifts as the miracles occurred. Only by realizing just how far down the rabbit hole of Alzheimer's we had gone can you begin to appreciate how wonderful it felt to have stopped the slide and actually have achieved the impossible and be climbing back out towards recovery!

Acknowledgements

My mum, Cathy, who, in her mid-eighties, and trying to recover from bowel cancer surgery and also the loss of vision in one eye, devastated at watching the long goodbye to her husband of over 60 years, kept her tears for many a long lonely night and stood strong for her children and grandchildren as well as being there for my Dad almost every day until the end.

My wife Jane, who fitted in so easily to our family. You were the rock for us all throughout these years, taking care of Mum and Dad in so many ways while keeping me sane in times that often felt like total insanity. My Dad loved you dearly, as do I.

Diana Buchanan, social worker and friend. You gave us direction so many times when we were in shock and lost. Your compassion for humanity was clearly demonstrated consistently as you went far beyond job requirements for us so often and so unselfishly. We would not have made it through without your wisdom and support.

Richard Swift, a true friend and ally who often helped me to re-strategize my efforts and hold laser like focus on the outcomes I was determined to accomplish.

My brothers Howard and John. You both provided unwavering support for Mum and Dad at every step of the way and were always there for me when I faltered.

Debbie, Manager at the care home where my Dad was placed. You believed me right from the start and did everything you could to help us get acceptance from the medical community and your support staff. You gave us hope and support as we took on the medical establishment on so many levels.

The Nursing and support staff at the care home—too many to mention individually. These people showed the highest level of compassion and commitment to everything we tried to do and are frequently denied the praise due to them for doing an amazing job in extremely trying circumstances.

John and Shiela Freil and family, close friends of my parents for 30 years. I could always rely on them to be there for my parents when needed. If,

while in my International work commitments, I became concerned as to how things were with my folks, I only had to call them and they would, unreservedly, drop whatever they were doing and drive over to check on them, then give me a call back. This alone made my folks (and my) experience, feel a lot more tolerable. I wish every family was blessed with friends such as these.

My Dad, Leo Howard Gilbert, 1920 *to* 2011. Your quiet courage facing the indignities, vulgarities and outrages of Alzheimer's was constant and exemplary. You faced it all with such a deep and amazing inner strength. May your story be inspirational for many and may it play a role in the ultimate delivery of mankind from the curse of Alzheimer's disease.

Part 1

This is a story of miracles and celebration, not just for my father and his family, but potentially for millions of other Alzheimer's sufferers and their families. The struggle faced by families in coming to terms with the stark reality of the effect of Alzheimer's and the numbing ripple effects which resonate in all directions is an area which has not been adequately addressed on any level. There is little or no professional help available to counsel family members through this protracted nightmare. For the most part we are left to flounder along, with each one of us dealing with it from his or her own personal perspective. It is an unsupportive and helpless environment with no hope for anything other than the certainty of a protracted physically, emotionally and often financially devastating terminal journey. This has to change in the future. However, in my efforts to come to terms with all of this I suddenly became aware of a very bright ray of hope for a potential cure and I was met with resistance on every level as I tried to get my father the chance he so desperately needed. How can a potential cure be simple and easily implemented? Your understandable current doubt and skepticism will gradually dissolve and you will be amazed at the potential of it all.

Chapter 1

The story you are about to read of the last two and a half years of my father's life has apparently become a glowing beacon for many people.

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My father was a strong, highly intelligent, articulate, athletic man who, after a distinguished career in the Royal Navy and Civil Service; worked in positions of trust well into his eighties; and rarely had a sick day in his life. He still spent much time tending to the affairs and not inconsiderable day to day voluntary running of the Stella Maris Organisation in Glasgow, Scotland.

He still lived at home independently with my Mum, his childhood sweetheart and wife for over 60 years and they led a full and dignified life with a huge circle of friends and family.

The fact that each year they would receive over 150 Christmas cards was a testament to the love and esteem they were held in within their community and beyond.

In 2005 (at age 85) he went into hospital for minor prostate surgery and while there he suddenly and shockingly contracted the "superbug" MRSA, which literally almost killed him within days (more on this later), however, despite the high incidence of fatalities from this, he found the inner strength to survive and to some extent recover. It was during the following few years that our family realized that all had not been well at work for Dad. It eventually became clear that he had not been working with full mental acuity for some time, in as much as mistakes and forgetfulness had been becoming more and more prevalent, but as he had no direct supervisor, we all (including Dad) were mostly unaware of how bad things were becoming. He, like most, became adept at keeping conversations to topics he could still relate to so unless you were unusually observant you would have thought he was as sharp as ever.

So, following the MRSA episode, Dad came home from the hospital and his physical recovery continued although mentally there were gradually increasing signs of forgetfulness and occasionally confusion. He still had a sharp intellect and an equally sharp sense of humour, however there were signs of his mental deterioration that were becoming harder to ignore, no matter how we tried to pretend otherwise.

Chapter 2

The walls came tumbling down. The illness finally revealed itself, and the effects on other family members gradually, though sometimes suddenly became evident and the devastating collateral damage of Alzheimer's manifested itself. How will you cope should the situation arise in your family?

There is little or no REAL help available to families trying to come to terms with the massive stresses of coping with the advent of Alzheimer's into their world, yet quietly living with the hardest feeling of all. That is the growing fear, emptiness and helplessness of fighting the inevitable tide of impending loss that gnaws silently and unspoken within, until it bursts forth in broken health in others. I am certain that the events that unfolded next are not uncommon scenarios for many.

The stress of coping with Dad's forgetfulness and ever increasing dependence upon her was building up on my Mum more than we realized. Dad had become increasingly possessive, asking where she went, who she was talking to on the phone, why she had to go out etc. (all normal signs of growing dementia and are no reflection on my Dad). She was also going 20 miles by public transport, two or three times per week, to help her almost house-bound older brother cope with life as a recent widower, plus go almost daily locally to her younger sister, who lived alone nearby and was coping with progressive terminal illness. So, besides bringing groceries to them and dealing with Dad, Mum really didn't have a lot of time for herself anymore. She had been a very social individual, a founder member of her church choir and loved not only to sing, but also the buzz of social interactions with her friends there. Gradually this social life had eroded until it was non-existent. She never complained and focused on her husband, brother and sister completely and unselfishly. Many a time shedding quiet tears as Dad lay sleeping beside her, she prayed for the strength to get through the next day and to keep the growing severity of the problem away from her sons and their families.

The stress on my Mum took its inevitable toll. While trying to cope and also prepare for the upcoming Christmas Season she became aware that something was not right with her own health and decided not to worry anyone and try to carry on as before. Finally her symptoms became so persistent that she saw her physician and, after going for further tests, she was unable to protect us any longer. The tests confirmed a malignancy in her bowel, requiring urgent surgery. She was told her chances of survival were questionable and that she would need to have the added insult to her dignity of a stoma (a bag attached to her abdomen) for the foreseeable future afterwards.

Suggestion #1

“You have an obligation to protect the caregiver (in this case my Mum) just as much as to protect and support the loved one suffering from Alzheimer’s.”

The one who is caring for the other is on a slippery slope to a breakdown in their health as well. They are caring for a loved one in often almost intolerable circumstances as the dementia increases. The constant worry and stress of dealing with the complete unpredictability of their loved ones behaviour takes an unavoidable toll. Do NOT listen to them when they stoically tell you that they are coping well. Either step in to help them yourself or get professional assistance involved in day to day care immediately. In retrospect I wish we had taken this step a long time before the end game kicked off.

Note: I have witnessed several families (thankfully not mine) where some of the grown children do not recognize the toll being exacted on the caregiving partner and have watched these partners deteriorate rapidly and often do not outlive their spouse! If you do not recognize and own the obligation to protect them, then the chances are high that you may be facing the impending loss of more than one family member!

(To further compound our scenario . . . on the same day, while Mum was being told the diagnosis, unknown to her, her younger sister [my aunt and godmother] who had suffered mightily yet stoically, was being admitted into

the Palliative Care unit of the nearby General Hospital and was given a short time to live.)

In shock, Mum returned home from hearing her own diagnosis, supported by her niece, and tried to tell Dad as gently as possible of what lay ahead. Although often confused, the impact of their words hit hard, he did not speak a word and within a few hours was experiencing a heart attack and was rushed into hospital, and admitted to a ward within meters of my Mum's sister!

Dad's cardiac symptoms settled over 48 hours yet physically and mentally he deteriorated rapidly in that ward and had changed within days from the image of a sharply dressed and mostly coherent individual to a seriously ill and physically weak man, wearing only a pyjamas and slippers, frequently incontinent of urine (or so it seemed), barely able to walk more than a few meters, and at times, having difficulty conversing sensibly with us. My wife, Jane would take his pyjamas home each night and wash and iron them without letting my brothers see, so that they would not be alarmed by his apparent incontinence.

I now put the prime reason for his rapid deterioration firmly on dehydration, and his apparent incontinence on high demands placed on inadequate numbers of staff in his ward, and will give my solid reasons for feeling this way later in this story.

There is beauty in every scenario in life however and it was a joy to us all to see his face light up with happiness each time my Mum came to visit him, which usually was twice daily. He even knew her footsteps coming down the hallway and would be beaming at her as she entered the ward.

Even to the very end he always seemed to sense her energy and would glow with happiness in her presence.

Once again my mother gathered her strength and held her head high as she ministered to her sister, to her brother and to my Dad, while making arrangements for her own surgery. She would not schedule it until she had helped her sister to pass, which somewhat mercifully happened within weeks and she scheduled herself to be admitted to hospital for her surgery literally within 2 hours of overseeing that her younger sister's funeral wishes had been honoured and fully implemented!

My Dad, while confused, somehow, in his lucid moments, clearly remained aware of the other traumas unfolding around him, and, true to character, tried to be of as little a burden as possible and kept his thoughts and fears to himself.

We did, with careful planning, manage to bring him home for a few hours on Christmas Day and he happily shared a Christmas dinner with us all as we all wondered what the near future would hold.

We as a family were now suddenly faced with the prospect of not only losing my Dad, but, due to the severity of Mum's diagnosis plus her physical and emotional exhaustion were also facing the unspoken possibility of losing them both. The walls of perceived family invincibility were indeed crashing down around us now.

End of Sample

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