

A Proposal for a Thesis in Creative Writing

Department of English

Bar Ilan University

Topic:

Walking with Papa's Wheelchair: Growing Up in the Shadow of MS

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הצעת מחקר לתיזה בכתיבה יוצרת

המחלקה לאנגלית

אוניברסיטת בר-אילן

נושא:

הליכה עם כיסא הגלגלים של אבא: גדילה בצל של תרשת נפוצה

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Introduction

Multiple Sclerosis, a chronic demyelinating disease of the nervous system, can take many forms. Some with the diagnosis may deal with minor annoyances such as reduced coordination or tingling digits while others will deteriorate until they eventually suffer from quadriplegia. My father was stricken with this more severe form of MS. Today, there are preventative medications that can slow the appearance of symptoms if a regimen is implemented close to early diagnosis. Unfortunately, thirty-five years ago, these medications did not exist and the myelin-eating was left to run its course. Throughout my childhood and young adulthood, I watched my father's physical condition decline from that of a young man who walked confidently with one crutch to a quadriplegic who can barely whisper.

What sets MS apart from many other illnesses is that it is chronic and debilitating but not fatal. Those living with more minor chronic diseases, such as arthritis, must adapt their lifestyles to address limitations and pain. Fatal diseases like cancer rarely last for more than a few years before taking a victim or being beat into remission. The intense form of MS my father has been living with for thirty-four years was constantly worsening throughout my youth, conquering one body part at a time, until he reached a state of complete paralysis. He and those around him know that each new disability is permanent.

In my memoir, I want to share what it was like as a child to grow up, watching my father wither before my eyes. In addition, I will share my adult perspective, reflecting back on my childhood. Throughout my eight years of marriage, my feelings about my mother's decision to marry my father, knowing how his illness might affect her life, changed a number of times. As a mother myself now, I will explore how my balance of protectiveness and encouraging my children's independence is connected to my childhood, as is how I educate my own children to accept others.

Aims and General Description

My father published a book in 2002 entitled *How to Back Up Without Giving Up*, a collection of autobiographical essays about living with MS and maintaining a positive attitude, republished in 2008 as a revised edition, *Never Give Up: Living Well Despite MS*. Indeed, the way my father approaches life and his illness has encouraged and guided me at various stages of my life. However, as the child of a sick parent, I often viewed my father's situation differently than him. I would like to share a memoir with my perspective, both as a child and as an adult, on my father's illness and how it affected my life. I will also attempt to paint a picture of who he was before MS struck and what he has continued to offer to his family, students, community, and friends, even with MS.

In addition, I will include details about both of my parents' lives in the form of narrative and scenes of memories they relayed to me. Their own early lives shaped who they are today and shaped their abilities to handle my father's disease as they did. In turn, the stories they told me about their childhood influenced my own. For example, they each lost a parent to illness at a young age, and this knowledge hung like a shadow over my childhood. Hand-in-hand with my perspective as a child, I will reflect as an adult and a mother on how I understand my parents and their decisions better now that I am a parent myself.

Conceptual Background

The written source that I will rely most heavily on while writing this thesis is my father's *How to Back Up Without Giving Up* and the revised *Never Give Up*. Since they are directly related to my father's life and my life, I will quote excerpts from these books and respond with my own perspective on events, as seen through the eyes of a child and reflection looking back on this childhood as an adult.

As preparation for and in the process of writing this thesis, I am consulting with a number of other books that are thematically related to multiple sclerosis, other chronic illnesses, and dealing with crises. Most of these books would be considered part of the self-help genre, the genre to which my father's books would probably be attributed as well. These include *Multiple Sclerosis for Dummies* and *Never Give Up!: Relentless Determination to Overcome Life's Challenges* by Joyce Meyer. I will read collections of true short stories about overcoming challenges, including *Children Courageous and Their Families* by my childhood pediatrician Frederick Roberts, which relates to how children and family members deal with medical crises and *Triumph: Inspiring True Stories of Challenge and Spiritual Growth*. I will also read works of fiction thematically related to MS such as *Never Never Never Give Up* by Miriam Joy Willms Neufeld.

I will consult memoirs such as Christopher Reeve's *Still Me*, about adapting to life as a quadriplegic and Erik Rees's *Never Ever Give Up* about the author's daughter who died from a brain tumor, for both content and stylistic decisions. *Tuesdays with Morrie*, by Mitch Albom, is particularly apt, since descriptions of Professor Morrie Schwartz's deteriorating condition are presented both in his own words, through dialogue, and through the eyes of the book's author, Mitch. My memoir will present two perspectives as well, not of two people, but of a child narrator and adult narrator with greater maturity and insight. In addition, I see a strong

parallelism between my father and Morrie, two Jewish social science professors from Boston, MA.

I will consult books that engage various perspectives on the same issue, such as Lucy Grealy's autobiographical essay *Mirrorings* about the agony she lived with surrounding her deformed face and how it impacted her emotionally, paired with her friend Ann Patchett's book *Truth and Beauty: A Friendship* about their relationship. Grealy felt a certain way about being disabled and standing out and Patchett held a different view. Likewise, my father and I lived through many situations together and have different views, that of the one sitting in the wheelchair and the one walking beside it or pushing it.

I will read memoirs about childhood such as *French Lessons* by Alice Kaplan. Kaplan artfully tells about her entire childhood and young adulthood as it centers around one theme, the French language. Similarly, I will attempt to focus my memoir around one theme, my father's illness. Other memoirs about childhood including *This Boy's Life* by Tobias Wolfe will also be consulted.

I will also read about different types of family relationships, including the parent-child relationship and spousal relationship. I have turned to *Why Mars and Venus Collide* by John Gray to research the effects of stress on marriage, since chronic illness causes significant stress on a family. Newspaper and journal articles also add to my knowledge of this topic.

Stylistically, I am modelling one chapter after Mary Gordon's autobiographical essay *My Grandmother's House*. Gordon describes her grandmother's house in vivid detail and the stages it went through, changing owners and conditions. The story of the house reflects the story of her life. The chapter in my thesis entitled "A Revered House", will illustrate the significance of place, moving from the raised ranch where I lived until age ten to the flat ranch where my parents have lived for the last twenty years. The move represents a turning point in my father's

capitulation to MS, the point at which the staircase to the main floor was simply insurmountable.

The style of my work will be based structurally on the style of Mitch Albom's *The Five People You Meet in Heaven*, which braids together a few stories about one person until his life story is told by the end of the book. Each story unfolds a few pages at a time, and a scene about the main character is followed by another character's view of what happened, filling in details the main character lacks. For example, someone died on his birthday, and he didn't know why; his birthday scene is followed by the dead person's narration of how he died. I will attempt to follow this structure by weaving together a number of thematic essays and juxtaposing them chronologically. Excerpts from my father's book and information about my parents' histories will be inserted in the form of scenes or narrative where relevant, throughout these essays.

My writing has also been influenced by a number of hybrid works of fiction including *The History of Love* by Nicole Kraus, which incorporates a number of narrators, each with a different style and medium of writing as well as *The Book Thief* by Markus Zusak. I do not intend to switch narrators throughout my book, but as Zusak included excerpts from other (fictional) works and even drawings in his book, I will include excerpts from my father's writings as well as a number of family photographs throughout my memoir.

Shape of Project

I aim to write a memoir that presents a different perspective on the illness than the sufferer. I would like to focus on how the illness effects the people closely involved with the one diagnosed, mainly family members. What was it like to be a child watching her father's decline in real-time? What effects did the disease have on me and the rest of the family, both practically and psychologically or emotionally? The thesis will take the form of a personal memoir comprised of a number of essays intertwined, unfolding one piece at a time, with the sections juxtaposed chronologically and sometimes associatively. The main threads will include, but not necessarily be limited to the following essays:

"A Revered House" discusses the two family homes I grew up in and illustrates my family life through the lens of these homes. The first was a raised ranch and the second was a flat ranch, which we moved to because it had no stairs to get in to the main level. This move represents a pivotal moment in my father's illness, when the family realized that he reached a point that stairs were impossible to climb. Subsections of this essay will sprout naturally from each room such as gardening outside, changes in my father's cooking career in the kitchen, and the evolution of the family's Shabbos table experience in the dining room. I will cover the entire span of time from my earliest memories in the house where my family lived when I was born, up to an including a description of the house where my parents live alone today. The structure of this chapter will be strongly influenced by Mary Gordon's story *My Grandmother's House*, in which she tells about herself and her family through a description of her grandmother's house.

"Out and About" will focus on my father's interactions with others outside the home. This will include a discussion of his work as a professor, community involvement, and his slew of regular appointments, to many of which I accompanied him. This section in particular will highlight how he has pushed himself to do as much as possible within his MS's limitations. I will

conduct interviews of former students, colleagues, and family friends in order to include others' views in this section. I will also show that how I felt about my parents' community work evolved as I grew up.

A third essay, as of yet untitled, will focus on times of crisis, such as significant hospitalizations and relapses. These incidents are the most stressful to all family members. I will discuss how I felt at the time and also touch on the feelings of other family members. This is where the contrast in perspectives of parents and children may be the clearest. How did I feel about my father missing my school play because he was in the hospital? How did my sister feel about him missing her sixth grade graduation because he was in the hospital? How did he feel about missing these important events in our lives? What about the times he was in the hospital for Jewish holidays? As part of this essay, I will quote excerpts from my father's books *How to Back Up Without Giving Up* and *Never Give Up: Living Well Despite MS* and relate to them from an opposing view.

Interspersed throughout these first three essays, I will include brief histories of my parents' lives before they met and in the first few years of marriage, before I was born, where relevant. This will help illustrate their perspectives on life in general and living with MS in particular, which strongly influenced me as a child and continues to do so today as well as give a greater context for the memoir. For example, the fact that both of my parents lost one of their parents at a young age caused me considerable angst as a child.

Whereas the first three essays cover the time period of childhood, when I still lived at home, the last essay, as of yet untitled, will focus on my life as a young adult, starting from ninth grade when I started boarding school. I will address how living away from home from age fourteen affected my relationship with my father, while his ability to communicate by phone and email has been decreasing. Seeing him only about once a month throughout high school

and once a year or less since then gave me a new perspective on his deteriorating physical condition. Suddenly, I could note specific changes in his abilities from monthly visit to monthly visit. This situation was intensified when I moved to Israel. Living away from home also granted me a certain amount of objectivity through distance, when I was no longer living with the MS every day. I could not write this book if I were still living close to my parents. This essay will discuss how my father's influence affects me as a parent. How do I treat my children differently because of it? What activities with my children remind me of doing things with my father? What kind of relationship do they have with their grandfather? How has our relationship changed now that I am an adult with my own children and am less "his little girl" (though I am sure I will be his little girl as long as we are both living)?

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