

## *Finding Meaning With Charles: Caregiving With Love Through A Degenerative Disease*

By Janet Edmunson

### • Information sheet

- Includes guides for: dealing with doctors, telling friends and family, maintaining a positive outlook, and much more.
- A wonderful resource for Hospice volunteers and staff.

In this inspirational and instructive book, Janet Edmunson helps others learn how to become supportive caregivers for loved ones enduring a debilitating and degenerative disease. Edmunson, a health promotion professional, cared for her husband Charles through a physically and emotionally devastating illness that ultimately led to his death in the same year the couple would have celebrated their twentieth anniversary.

Charles left many legacies and admirers, but one of these legacies was left for just his wife. Through the course of his life and then his disease, Edmunson learned the keys to becoming a supportive caregiver for a loved one who is ill. Her book teaches others how to help their loved one fulfill whatever aspirations are still possible, all the while becoming a stronger person because of the experience.

Edmunson offers *Caregiving Affirmations* with each chapter and guides to how to deal with issues like; learning more about the disease, dealing with doctors, telling family and friends, and helping a loved one get through illness with dignity and a positive outlook. The book also helps caregivers cope with the emotional and physical challenges they will face during the course of an illness and help them “get to the other side”.

### Advance praise:

Unlocks the reader’s vulnerabilities as the sharing of **everyday details is interwoven with larger spiritual understandings** regarding the nature of disease, loss, and relationship. The author has used the complexity and richness of the experience to “make meaning” and to accomplish the difficult task in grief of holding the past and bringing it forward to the now.

—Edith L. Murray, *Hospice Administrator, Wayside Hospice, Wayland, MA*

This uplifting book will encourage caregivers to make the most of their situation, help them understand the difficulties they'll face, and teach them what they can do to help their loved one achieve personal aspirations....A **"must read"** for caregivers of degenerative neurological diseases.

—Richard Zyne, *D.Min. Executive Director, Society for Progressive Supranuclear Palsy*

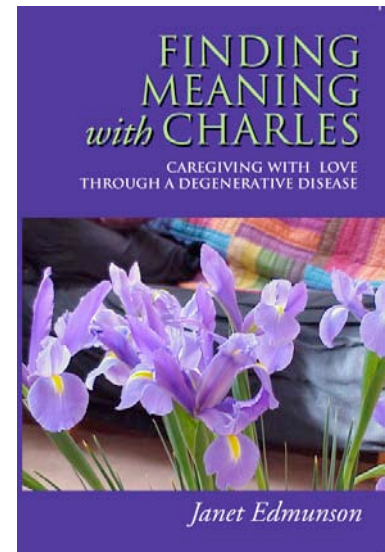
I have walked in Janet's shoes as a caregiver. Caregiving is a true test of love and endurance. As a caregiver, you will be overwhelmed. **This book will give you an incredible sense of peace and acceptance and the affirmations will bring you comfort.** I wish the book were available when I struggled with my journey.

—Patti Ryan, *loving companion and caregiver for Leo Hamel during his neurological disease.*

### About the Author:

**JANET EDMUNSON** is an inspirational speaker, writer and health promotion professional, who is dedicated to using her life experiences and inner values to support the growth and self esteem of the people her life touches. Janet has over 30 years experience in health promotion, most recently as **Director of Prevention & Wellness for Blue Cross and Blue Shield of Massachusetts**, where over the last 10 years she has lead a team of 20 professionals in creating and implementing programs to improve the health of their nearly 3 million members.

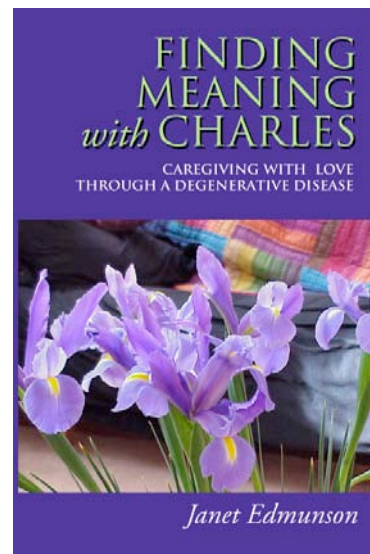
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• **Questions and answers with author Janet Edmunson**

**1. How did you decide which stories about your experience with caring for Charles to include in the book?**

I tried to tell the stories that I thought would be most helpful to caregivers in understanding not only the caregiving experience that I had with Charles, but also the context of our relationship together. Also the writing group I'm a part of was instrumental in helping me understand which stories hit home and those became the stories I felt would have the most impact for others.

**2. What is the most important message you'd like people to get from reading the book?**

I really want caregivers to know that they can get through this life-changing event but still keep a positive attitude. Staying strong and positive will help them as well as their loved one survive the difficulties, and by doing so, they will also be able to make meaning out of this tragedy.

**3. Did you find it difficult to share some of the stories in the book? If so, which were the most problematic and what did you learn from that story or stories?**

The most difficult story to share, and to live through as well, was when Charles told me that he loved his aide. At this time in the course of his disease, he was telling every woman nurse that he loved them and here I was taking care of him at every step! I knew intellectually that the disease had broken down his normal brain filters which took away his sexual inhibitions. But for me emotionally, the pain was still excruciating. Could he really have fallen in love with someone else while I was giving my all to care for him? The truth I knew intellectually did not always overcome the fears of possibly losing his love.

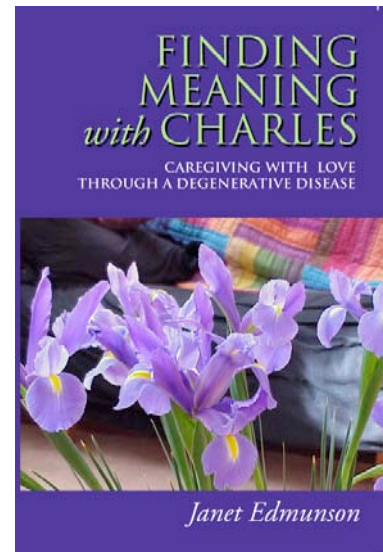
**4. How would you like people who read the book to use the affirmations you present?**

I want people to find inspiration from the affirmations. I would love for caregivers to select even just one or two of the affirmations that they can relate to and then hold on to, even whisper the affirmations to themselves on a regular basis. They might post them on the mirror in the bath room or write them in places that would remind them that they can get through this tragic time. Through the affirmations, I hope they will see how this event is making meaning in their lives.

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• Questions and answers (continued.)

**5. What prompted you to write the book?**

While Charles was declining with his disease, our friends helped me work with him to write and publish his own book, *Paradoxes of Leadership*. I realized then that if we could get Charles's book written and published under such difficult situations, I could write and publish a book myself, and the idea was fueled when Charles's Hospice nurse commented to me one day about my positive attitude. My attitude was something I didn't even think about! I asked her "doesn't everyone have this perspective to help get through this type of situation?" She told me that it was rare and that many people can't cope with situations like the one Charles and I were in. I had never planned to write a book in my life, but that confirmed my decision to write this book. I knew I had a story to tell that I hoped would help other caregivers get through with a positive outlook, in spite of the tremendous difficulties and sadness, just as I was able to do.

**6. What have been some of the challenges you faced in writing the book?**

Most of the writing I had done previous to this book were health promotion related, which is very different from telling my personal story. I had the hardest time conveying my feelings and emotions when writing the stories. I just found it easier to talk about the events than to dig deep within to understand and then be able to write about my feelings. My writing group friends would often say "We want to learn more about you, and what you felt." That helped me focus on making sure that I did address the feelings and not just the events.

**7. Who do you think might benefit the most from reading the book?**

My hope is that anyone would find meaning and value in reading this book. But I'm sure it will speak most strongly to those that were or are in the situation that I faced—having a love one slowly slipping away due to a degenerative disease.

**8. How has writing the book affected you personally?**

When I told people that I was writing the book, many commented that the process must have been cathartic. And yes, I suppose that writing the stories helped me process the tremendous loss of Charles from my life. But I also think that writing the book helped me to see more clearly where the meaning was in this tragedy. The profound sadness of the stories didn't overwhelm me during the writing, but often does when I read them.

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### ***Neurological Disease Statistics***

Over 6 million people in the United States suffer from some kind of degenerative neurological condition.

#### ***Parkinson Disease***

([www.apdaparkinson.org/user/AboutParkinson.asp](http://www.apdaparkinson.org/user/AboutParkinson.asp))

- The American Parkinson Disease Association estimates that more than 1.5 million people in the United States have Parkinson disease.
- More than 2.3 million dollars a year is allocated by the APDA to support research.

#### ***Alzheimer's Disease***

([www.alz.org/AboutAD/Statistics.asp](http://www.alz.org/AboutAD/Statistics.asp))

- The Alzheimer's Association estimates that 4.5 million people in America have Alzheimer's disease and that 19 million people have a family member with the disease.
- The number of American's with Alzheimer's disease has more than doubled since 1980. By 2050, the number could range from 11.3 million to 16 million.
- More than 7 out of 10 people with Alzheimer's disease live at home, where family and friends provide almost 75 percent of their care.
- The average lifetime cost of care for an individual with Alzheimer's disease is \$174,000.
- National direct and indirect costs of caring for individuals with Alzheimer's disease are over \$100 billion.
- Alzheimer's disease costs American businesses \$61 billion a year. Of that figure, \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement. The remaining \$24.6 billion covers Alzheimer health care.

#### ***Progressive Supranuclear Palsy (PSP)***

([www.psp.org/education\\_center/facts\\_about.asp](http://www.psp.org/education_center/facts_about.asp))

- According to the Society for Progressive Supranuclear Palsy, this is an under-recognized brain disease without firm estimates of the prevalence.
- PSP is an under-recognized brain disease. Dudley Moore suffered from PSP and it received attention when he shared his diagnosis.
- Experts from the Society estimate that 20,000 Americans have been diagnosed with PSP, while many others have PSP but have been misdiagnosed.

#### ***Multiple Sclerosis***

([www.nationalmssociety.org/Who%20gets%20MS.asp](http://www.nationalmssociety.org/Who%20gets%20MS.asp))

- Every week about 200 people are diagnosed with multiple sclerosis in America and an estimated 400,000 are suffering from the disease, according to the National Multiple Sclerosis Society.

#### ***Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig Disease)***

([www.alsa.org/als/who.cfm?CFID=1526074&CFTOKEN=13289409](http://www.alsa.org/als/who.cfm?CFID=1526074&CFTOKEN=13289409))

- The ALS Association estimates that 30,000 Americans have ALS.

