

An Excerpt from *Caregiving with Strength*

Author: Eleanor Silverberg



The Author's Note about Caregivers

A word about caregivers

The responsibility for primary, ongoing care of adults with chronic conditions such as Schizophrenia, Acquired Brain Injury, Alzheimer's, Parkinson's and Huntington's disease usually falls on the shoulders of the family. Although family members do not sign up for the job willingly, they manage to fulfill the obligation to the best of their ability, making a major contribution to the health care system.

Recognizing the challenges family caregivers face, including the risk to their own health, this book has been written exclusively for the family caregivers and the professionals who service these families. The objective is to address the challenges faced by family caregivers, strengthening resiliency by providing a strength-building regimen.

Often the family members are overlooked, with the focus of care being on the chronically ill care recipients. By attending to the family caregivers' well being, which is in the goal of this book, the care recipients who are dependent upon them also benefit.

A word about "caregiver" as jargon

One of the many things I discovered when I started my private practice as a social worker and self-development coach for care providers was that each profession has its own language. Those outside the profession may need an interpreter to understand the language. I discovered this through the meaning of the words "caregiver" in the health care profession and "brand(ing)" in the business profession.

Upon pursuing self-employment coming out of social service, I took some business courses and obtained a business coach. I repeatedly heard the word "branding" which automatically made me think of cows. I eventually caught on that "branding" was related to business image. I also discovered that, just as the word "branding" is not easily understood by people outside of the business world, the word "caregiver" is not easily understood by people outside of the health care system, and that also includes the family members who provide care but are not identifying themselves as caregivers. Although not used by a major portion of the population, the words "family caregivers" are thrown around mindlessly among professional health care workers.

At the start of self-employment training to identify as a health care professional, I proceeded to describe my business, throwing the word "caregiver" around several times since my practice revolves around *assisting* people who are providing care. My coach, coming from the field of business, was throwing around the word "brand" as much as I was throwing around "caregiver." Yes, we were from the same planet but obviously living in different worlds. After some time, I no longer associated "branding" to cows and my business coach stopped associating "caregivers" only to people who get paid to come in and take care of the disabled.

An Excerpt from *Caregiving with Strength*

Author: Eleanor Silverberg

The communication difficulty with my coach raised my awareness, drawing my attention towards the need to be clear with whomever I am speaking around the definition of caregiver. It is also important to discuss with those providing care their perception regarding identifying themselves as caregivers.

While on the topic of language, throughout this book, I have used the words “caregiver,” “carer” and “care provider” interchangeably when referring to a person who is providing assistance to an individual who is not able to function independently due to illness. Furthermore, I have attempted to be general in order to incorporate those caring for a number of different illnesses. Although many of the examples used are related to dementia, they may be applied to other chronic or progressive illnesses. In other words, if the specific chronic illness that you as the reader are dealing with is not mentioned, you can still benefit from this book.

Who can consider themselves as a caregiver, a carer, or a care provider?

Once individuals identify themselves as caregivers, it can really stick with them. In www.allnurses.com, I read a true story relayed by a nurse who works in a long term care home about a very confused resident with dementia who used to be a nurse. Staff often needed to redirect her away from helping others as she was thinking in her confused state that she was their nurse. The long term care nurse relayed a specific incident where she caught the confused ex-nurse attempting to help up a very large fall risk resident and was directed by her to get a walker and a gait belt so that “we” can get him ambulating.

This anecdote demonstrates how instilled the identity can get once an individual *acknowledges* herself or himself as a care provider. Often though, professionals and family members do not identify themselves as “caregivers.” It can also be rather confusing since there are so many contexts in which one could be identified as a caregiver. Formal or professional care providers are doctors, nurses, social workers, psychotherapists, personal support workers and other health care workers. Informal caregivers are family members, friends, or neighbors providing a critical sustaining role for frail or disabled individuals who are unable to carry out activities of daily living.

Another word frequently used in health care is “primary” in reference to the carer. A primary caregiver in the case of dementia can be the one who makes the major decisions on behalf of the care recipient who is no longer able to make his or her own decisions due to the progressive loss of cognitive functioning. Primary caregivers frequently hold the power of attorney, a document that allows them to act on behalf of the care recipient. Most often it is a spouse or adult child who is carrying out the bulk of the responsibilities. It is a demanding job for one person and often there is assistance provided by other family members or supports outside of the family.

Some of the many ways in which you, as a family member, are caregiving is if you:

- Do shopping for an aunt.
- Take your spouse to medical appointments.
- Remind your grandmother to take her pills.

An Excerpt from *Caregiving with Strength*

Author: Eleanor Silverberg

- Pay the bills for your parent.
- Provide relief for a caregiver.

A 2012 Statistics Canada study found that 28 per cent of Canadians aged 15 or older were caregivers to family or friends with various long term health conditions. I am not certain what constituted being referred to as a caregiver in that study. You can be sure, though, that as time goes on, that number is going to increase.

As our population is aging, there are going to be more people who are providing care for older adults with chronic and progressive illnesses. With chronic and progressive illness, a family member can be providing care for several years. There is already a shortage of human resources in the health care system to accommodate the need – leaving the greatest responsibility of the caregiving to the family. The caregiving may fall more on one family member than another. The caregiver may be living with the care recipient, living nearby or far away, each scenario having its own challenges.

The level of care given to family members with a chronic illness is based on a number of factors including the care recipient's needs, caregivers' health, whether or not the caregivers are living with the recipients, and the amount of supports available. This book can serve any of the family caregivers – at any level – who require *assistance* in strength building for the sake of their own health and the health of others.