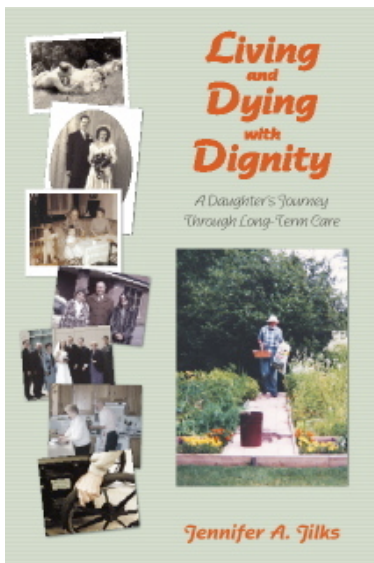


Jennifer A. Jilks
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Living and Dying With Dignity:

A daughter's journey through Long-Term Care



Biography

Jennifer Jilks, retired teacher and educational writer, moved to Muskoka to care for her failing parents. Her intent: to write a book about teaching. Leaving behind friends, family and support systems, she was forced to retire early due to caregiver stress, depression and burn-out. Rather than the book about teaching, she participated in helping her parents navigate through end-of-life issues and wrote of her journey helping her parents die with dignity.

Her mother died at home from cancer, and her father from a brain tumour while in Long-Term Care. Part memoir, part research, the book includes coping strategies, and information discovered about the maze of Ontario Health Care options. *Living and Dying With Dignity* follows her parents' journey, carefully explaining what happens after the diagnosis of cancer. Many have written success stories, but how do you cope when cancer or a brain tumour returns, when juggling as an adult child and a caregiver? What are your rights?

Author of many educational publications, and a school teacher from grades JK to 8, with workshop presentations ranging from Internet Safety, Web Design for Students, Integrating Technology for Exceptional Students, Jennifer has turned these skills towards adults.

Her work with the young has been transferred to working with older adults as a Peer Health Educator with the Cardiovascular Health Awareness Program, a Consultant with the Provincial Aging at Home Strategy, and a blogger: ontarioseniors.blogspot.com

The book's first section is a memoir, which deals with the emotions of relocating, finding care and suitable supports for her parents. The second section is a research-based section with helpful advice. Since the senior generation are often reluctant to ask questions, and people often don't know which ones to ask, this book includes information about your rights as a patient, i.e., treatment plans, discharge options, and questions to ask your oncologist. You have a right to know treatments, treatment symptoms, options, and quality of life issues. There are many barriers to getting health care in Canada.



Suggested questions for discussion

1. **Tell me why you were inspired to write this book?**
2. **When did you realize that your father was as ill as your mother?**
3. **How is a caregiver's health impacted by the work demanded of caregiving?**
4. **What is happening to the sandwich generation as aging parents demand and require major support?**
5. **What are the most important lessons you learned while caring for your parents?**
6. **The Ontario government has been spending money in areas such as new Nurse Practitioners, Aging at Home Projects and Family Health Care Teams. Do you think these solutions are working?**
7. **Many caregivers are facing ill-health, as you suffered from depression. What advice do you give to caregivers?**
8. **What recommendations do you have for the government?**
9. **What is the difference between Long-Term Care and Retirement Homes?**
10. **Why is it so important to identify the symptoms of dementia and/or delirium early on in the process?**
11. **What questions should patients ask of their physicians and oncologists?**
12. **The final section of your book contains important conclusions about senior health care and reflects on some of these initiatives. What are some of these ideas?**

Information about aging in Ontario

With an aging senior population, Canada has few geriatricians. Typically, Family Physicians are untrained in geriatrics.

Those who work with seniors do not necessarily have training. Personal Support Workers (PSWs), who do most of the work in LTC and Retirement homes may have only a 14-module training course. They need to be regulated and monitored as do those who work with young children.

Many family members do not know how to access services. Many are as ill as their family members. Many seniors are themselves caring for ailing seniors, with little access to home care (4 hours per day in Ontario).

Hospitals are places for those with acute illnesses. They do not deal well with those who are frail. As a caregiver, expect that you will be of benefit to them if you are present at their bedside. There is much to do. It is important to advocate for them; record treatment plans, medications, test results. Be proactive. Ask Why, How often and How much? With 3 new



medications, seniors are at high risk for complications. About 50% of those with dementia are at home. Two-thirds of these remain undiagnosed. Dementia, often confused with delirium, is under diagnosed in many seniors; both are treatable and can be ameliorated.

It is estimated that dementia is present in 23% of seniors aged 85-89, 40% of seniors aged 90-94, 55% of seniors aged 95-99, and 85% of seniors aged 100-106.

Advice for caregivers and family members

- Go to doctor's appointments with your family members.
- Be prepared with questions about treatment plans, treatment side effects, the impact of treatment on one's quality of life, as well as survival rates from the treatments.
- Keep a medical diary of symptoms and treatments and take notes.
- Understand the difference between dementia and delirium.
- Balance your social and emotional needs with those of your parents.
- Caregivers must act in the interest of safety in terms of health, nutrition, and access to the wheel. It is estimated that 20% of dementia patients are still driving.

Barriers to health care

- Lack of patient advocates, like the Alzheimer's Society FirstLink.
- Geographical inequities across the province.
- Transportation
- Lack of qualified personnel from geriatricians, nurses, to PSWs.
- Health care relies on unqualified community supports: churches, neighbours, rather than hospice volunteers, and PWSs.
- Ailing spouses may be unable to provide adequate care resulting in Elder Neglect and Abuse. This can be prevented or ameliorated with CCAC intervention.
- Myths around pain and pain management
- Family issues - dysfunctional families
- Communication deficiencies or disorders: language barriers, auditory, visual, cognitive disorders
- Denial of health issues by seniors, family and friends
- Bias or prejudice - i.e., inaccurate statistics: women die of stroke and heart disease
- Fears - of diagnosis or treatment
- Patients who do not speak English
- Poor or ineffective treatment plans



- Cognitive disorders - delirium, dementia,
- Mental health issues
- Mistakes in diagnosis
- Attitudes: i.e., discrimination, being treated as incompetent, expressive or receptive language disorders
- Primary Care workers who speak down to patients, or use acronyms, or complicated language
- Wait times, lack of staffing, crowded hospitals where seniors do not have enough support, are immobile, and may not get all the nutrition they need.

Recommendations for the government

- **We need more geriatricians.** End-of-life is a much more complex stage of life than pediatrics. Every Primary Care staff member needs training in geriatrics from the physician or nurse to the PSW.
- **We are short-staffed in Primary Care**
- **Delivery of Health Care in Central & Northern Ontario requires as infusion of money and beds, not less.**
- **Regulation and Registry of PSWs.** In profit and non-profit care we allow personal support workers to provide intimate care to loved ones. To work in Day Care you need an ECE degree, yet PSWs may or may not have a certificate from a college. This must be changed.
- **Patient Advocates.** Each senior should have a patient advocate to support the entire family, not just the patient.

Resume

- Special Education teacher for over 25 years.
- Wife, mother of 3 adult children, one granddaughter
- Board of Directors member for FYCSM.ca
- Workshop presenter to elementary, university and adults
- Internet expert and published author on education, web design and internet safety.
- Consultant with the North Simcoe-Muskoka LHIN's Aging at Home Project
- Trained Hospice volunteer
- Trained Volunteer Crisis Responder
- Peer Health Educator with CHAP -www.chaprogram.ca