

## Caring for the Caregiver

Currently, more than one in 10 Canadians is over the age of 65. By the year 2021, it is estimated that this number will increase to almost 18% of the population or 6.7 million people. Approximately 80% of eldercare is provided by family members. The Berger Monitor has estimated that there are 4.5 million caregivers in Canada who spend about \$100 million a week—\$5 billion a year—on the incidental expenses of caregiving.<sup>1</sup> This doesn't include the inevitable emotional stresses of caregiving, and their attendant physical side effects.

Enter Karen Henderson, a woman who spent 14 years caring for an elderly father, frustrated and overwhelmed by the

lack of available resources for caregivers. In her own words “If I had known back in 1986 what I know now about caregiving, I could have saved myself considerable worry, frustration, anger, illness and guilt...I know I would have been a healthier, more effective caregiver.” Karen's father passed away in April of 2000, but not before his experience had left an indelible impression and formed a sustaining passion.

Karen, who has a background in sales, marketing and adult education, took her experience and launched The Caregiver Network, a combination information resource, service directory and support network. CNI, the first program of its kind in Canada, was initially launched in 1996 as a website, and soon began registering hits from all over the world. Recently, Karen has launched a second website, How to Care.

The Caregiver Network site provides a comprehensive list of support groups, nursing homes, federal and provincial agencies and a medium for caregivers to express their thoughts and feelings. There are sections detailing the importance of advance directives, power of attorney and substitute decision-making, along with contact numbers for the Public Guardian and Trustee's office. The site also has contacts and information on geriatric day care programs, support for caregivers and forums on a variety of diseases of the elderly. One of the most compelling resources on the site is Karen's personal diary, *On my mind*, which details her thoughts and feelings during the period of care for her father, who suffered from dementia and died in a long-term care facility.

The second website, How to care, provides more detailed health and support information on a variety of issues that a caregiver may face. According to the site, “How to Care is here to help you manage the realities of caring for others and yourself by supplying practical, portable information on the issues we know you will confront.” The topics are divided into sections on ‘Day to Day,’ ‘Conditions/Diseases/Situations,’ ‘Help/Support,’ ‘Practical Solutions,’ and ‘Communication.’ Each section is further subdivided into topics such as ‘Incontinence,’ with a brief glossary of terms, definition and relevant information for the caregiver on managing some of these issues.

The services provided by the Caregiver Network and How to Care, go beyond the web resources. Karen also publishes a quarterly newsletter *The Caregiver*, and was involved in the production of a television series, ‘Caregiving with June Callwood,’ a 13-part TV/video series that tackled caregiver issues. She produces a Personal Care binder, designed to help caregivers keep track of critical personal and medical information needed when coordinating care for a loved one at home. Karen is also available to give seminars to both family and professional caregivers.

I invite you to visit the sites for the Caregiver Network and How to Care at [www.caregiver.on.ca](http://www.caregiver.on.ca) and at [www.howtocare.com](http://www.howtocare.com).

### Sources

1. September 1999 Berger Population Health Monitor.