



Family Caregivers
of British Columbia

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CLOSING THE GAP

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Providing long-distance caregiving for an aging parent can be fraught with logistical and emotional hurdles. Marcia Kaye investigates this largely uncharted territory.

For 30 years, Judy MacLean of Halifax had been flying across the country several times a year to see her mother back in Calgary. Over time, the caregiving duties increased. So, naturally, MacLean assumed that when her mother needed more care than the Calgary retirement home could provide, MacLean would bring her to live in Halifax. Last year, as the 92-year-old widow began to experience more and more confusion, MacLean put her mother's name on a list for an apartment in a senior's home in Halifax. Trouble was, while the older woman understood that she needed more assistance and would be moving, she hadn't realized she'd be leaving Calgary.

One day the home-care worker remarked casually to MacLean's mother, "Oh, you'll like Halifax."

"Halifax?" the older woman repeated in shock. "I'm not moving to Halifax!"

That's when MacLean realized that her role as a long-distance caregiver was far from over.

Long-distance caregiving for an aging parent represents an area of largely uncharted territory in Canada. No one knows how long it's been going on, but it's been suggested that where the '60s generation gap was psychological, the current one is geographical. Every five years from 1980 to 1995 more than 40 per cent of the population moved, mostly for work related reasons, often leaving the older generation hundreds or thousands of kilometers away from their children and grandchildren. Of the more than two million Canadians providing care to a frail senior, it's estimated that half a million live at least an hour's travel time away. It's a situation that can only continue to multiply. Today there are 3.6 million Canadians aged 65 or older; a generation from now, that figure will more than double to eight million.

Eldercare at a distance seems fraught with logistical hurdles, whereas moving our parent in with us seems the right and noble thing to do. But that may cause more problems than it solves. "It can work out, but it most often doesn't," says Jill Kelly, founder of the Toronto-based CGC Group, a private care-management company. Kelly recalls that when her own grandmother moved in with the family, stress levels soared. "It's an infringement on everyone's privacy, including the grandchildren. It can demolish marriages."

Most seniors want to stay in their own familiar community anyways, as MacLean discovered when her mother so adamantly refused to leave Calgary for Halifax. It left MacLean in the position of continuing to manage her mother's care from 3,500 km away. In March she moved her to a government-subsidized complex of individual houses in Calgary, each house having 12 residents, staff and its own kitchen, dining room and common room. MacLean, who put tremendous thought and effort into planning the move through several visits to Calgary, is still trying to persuade herself that it was the



right decision. “Sometimes I think about what my mother is missing by not being in Halifax, like seeing her two-year-old great-granddaughter,” says MacLean, who works as the library coordinator for the Nova Scotia Centre on Aging. “But then I have to remind myself that a two-year-old would be very tiring to her. I’m still hanging on to the image of my mother as she used to be, instead of anticipating what she may need and want in the coming years.”

While some seniors require the 24-hour care of a nursing home, the vast majority do not. In fact, the popular notion that our society warehouses its old people in nursing homes is largely unfounded. Currently, 98 per cent of Canadians aged 65 to 74 live at home, as do 85 per cent of those aged 75 to 84, according to a 1988 study by the Urban Futures Institute of Vancouver. “Given the way the health of seniors is going, the probability that they can stay in their homes for longer will keep getting higher,” says Andrew Ramlo, the research associate who co-authored the study. And improved home-care services, such as home-based dialysis, mean that even seniors with chronic illness can remain at home. A 1997 study by Health Canada found that four out of five seniors living at home have been diagnosed with a chronic health condition, such as diabetes, arthritis or heart disease.

Vancouver writer John Keyes is a long-distance caregiver to his parents, who live in Thornbury, Ontario. For years, when Keyes lived in Toronto, he would make the two-hour drive to spend the day. Now he visits three times a year, staying with his parents for a week at a time. Since his father has had a heart attack and his mother has a foot problem that severely limits her mobility, Keyes has increasingly given his parents gifts of products and services they can really use. Two items that they didn’t know they needed (but now can’t live without) are a cordless phone and a garbage can on wheels. “For Christmas a few years ago I bought Dad snow removal for the winter,” Keyes says. “This was the perfect opportunity to get him to give up shoveling, while maintaining his dignity. He’s a sharp cookie and he knew exactly what I was doing. Still, he renews the service himself now every fall.”

Keyes encourages his parents to draw up a to-do list for him before each visit. It might include caulking around the bathtub, taking the duvet to the Laundromat (it’s too big for his parent’s washer) or moving a heavy piece of furniture. Twice a year Keyes changes all the light bulbs in the house whether they need it or not, so his parents won’t be caught in the dark when a hard-to-reach bulb burns out. His parents save the still-good bulbs for things they can easily reach, such as table lamps. During his visits Keyes does the grocery shopping and cooks all the meals, including a turkey dinner. Before he leaves he carries up from the basement everything that his parents might need for the next month or two, such as canned goods and tools. The infrequency of his visits tears at Keyes. “They’re wonderful people, and I feel bad that I don’t see them as often as I used to,” he says. His mother, however, views the situation quite differently. “A solid week when he can visit like that is worth a year of Sundays,” says Mary Keyes, 79. “John can sit and read a book, watch some television, go for a walk with his father. It’s more like natural living.” She adds, “The best thing John does for us is talk about the things he’s doing and the people he has met. He brings his world to us.”



Men like Keyes are not as rare as we used to think. While it has long been assumed that women do almost all the eldercare in this country, a new Statistics Canada survey found that of the two million people in Canada giving care to seniors, 40 per cent are men. What's even more surprising is that men reported feeling significantly more guilty than women. "I think that men now recognize the importance of caregiving and they value it, but they realize they're not doing as much of it as women," says Norah Keating, a professor in the department of human ecology at the University of Alberta in Edmonton and co-author of the Industry Department's *Eldercare in Canada: Context, Content and Consequences*. Men reported spending three hours a week on caregiving for a senior, as compared to five hours for women.

Another new finding in the study is that the most stressed-out caregivers are not those who live farthest away from their parent, but those who live within one or two hours' driving distance. Keating says, "These commuting caregivers have been almost invisible, yet they're the ones juggling work and curtailing their own activities and even their sleep. I'd say a high proportion of them are at frilly high risk of health consequences."

Reva Nelson has been a commuting caregiver for 20 years. Nelson, a seminar leader and author, lives in Toronto, while her 84-year-old mother lives in Hamilton. In ideal conditions, it's a one-hour drive; in winter weather or summer traffic, it's two hours or more. Nelson's mother, who has an active mind but is physically disabled from Parkinson's disease, lives in an apartment with a full-time caregiver. Nelson has considered moving to Hamilton, but as a single mother, she can't afford to give up her business. Nor does her mother want to move to Toronto.

Nelson is grateful for the excellent home-care workers, the doctor and dentist who make house calls, and her two brothers who share the caregiving. Still, she often feels timecrunched from her regular Sunday visits, during which she buys the week's groceries for her mother, takes her flowers, magazines, lotions and pretty nightgowns, and spends the day. She also rearranges her weekday schedule so she can take her mother to specialists' appointments. Even with all the support, Nelson finds there is always care management to do. "When the caregiver was going on holidays, I must have spent a minimum of 20 hours on the phone finding a replacement situation," she says.

While Nelson willingly visits her mother, she and her brother recently decided to stagger their visits, so that each goes every second Sunday. This way, their mother is not overwhelmed with an apartment full of visitors at once, and Nelson has more time for herself on alternate weekends. Experts agree that the caregivers who fare best are those who say to themselves, "Well, I've done everything I can this time. Now I need to get on with my own life."

Like Nelson, most people view their caregiving duties not as a burden but as a strong moral obligation. They recognize not only what their parent has done for them in the past, but what their parent continues to offer, says Janice Keefe, an associate professor



in the family studied and gerontology department at Mount Saint Vincent University in Halifax, who has studied the reciprocal relationship between adult child and elderly parent. Keefe says, "While older parents tend to see themselves as burdens, children are more likely to remember how their parent helped them buy a car, pay for a university education, let them move back home after a marriage breakup, or looked after the grandchildren. Even if there's a distance between you, the emotional support can continue to flow back and forth." Keefe adds that no matter how dependent or childlike your parent may become, role reversal should not happen; your parent is still your parent and you are still the child, and you have a history together that time can never reverse.

While caregivers who live near their parents may see them regularly, it's often the longdistance caregiver who notices subtle health changes. Lorna Hillman of Victoria sees her parents, who live in Edmonton, less frequently than her four siblings do. But she says, "I was the one who alerted my brothers and sisters that our father was suffering from more than just a bad memory." Sure enough, her father was diagnosed with the beginning stages of Alzheimer's. He still lives at home, with help from home care, mostly financed through Veterans Affairs Canada. Hillman, who is executive director of the Family Caregivers' Network Society, an information and support centre in Victoria, says, "Caregivers wait an average of six years before accessing any services such as home care. It's not necessary to go to such heroic lengths." (For more information on home care, see To Help You Cope on next page.)

In some special cases, help can arrive in other than human form. When Doris Knight, 78, of Cambridge, Ont., was diagnosed with early Alzheimer's, her husband, Bill, became increasingly uncomfortable about leaving her alone in the house while he went to do errands or play golf. Doris could still function, but when the house was empty, she would simply sit, unfocused. Their children, all three of whom visit frequently, couldn't offer help on a daily basis: one son lives in Calgary, the other in Ottawa, and their daughter, who lives nearby, works full-time. But on the advice of a woman who works with Alzheimer patients, the three children decided to get their parents a dog. Not a high-maintenance puppy, but an eight-year old miniature schnauzer. It worked beautifully. "That dog was her companion when Dad was gone," says Bob Knight, the son who lives in Calgary. "She would pet it for hours, and it would follow her around the house. It gave both Mum and Dad a focus and a purpose and a schedule. They'd say, 'It's 10 o'clock. Time to take the dog for a walk.'"

After a year, Doris's Alzheimer's had progressed to the point where her husband could no longer care for her, and she now lives in a nursing home. But Bob says, "For that year, getting the dog was absolutely the best thing we could have done."

While all families have to figure out for themselves what works for them, experts have one common piece of advice: think ahead. Try to anticipate your parent's needs, so that when more help is needed,



you'll have some options to present. And if you're not yet in the position of caregiver, assume that one day you will be. Hillman of the Family Caregivers' Network Society says, "For the majority of people, it's not a matter of if you're going to become a caregiver. It's a matter of when."

To Help You Cope

Before a crisis forces you into it, develop a plan for long-distance caregiving.

- Bring your siblings and parent together to discuss what the needs are. If you foresee disputes, consult a family therapist or social worker.
- Start building a support network in your parent's community. Ask a trusted neighbour or a member of your parent's religious or social organization to call you (collect) with any concerns. Stay in touch with your parent through e-mail or regular phone calls.
- At your parent's home, keep a care log to record information such as medication, dietary restrictions and equipment needs. The Personal Care Binder, developed by the Caregiver Network and now used by the geriatric outreach program at Sunnybrook and Women's College Health Sciences Centre in Toronto, is available for \$25. Call 416- 323-1090 or contact www.caregiver.on.ca.
- At your house, keep information about your parent close at hand. Audrey Henderson, coordinator of the Family Caregiver Centre in Calgary, suggests the following: date of birth; social insurance information; list of medications (keep it current); names and numbers of doctors; copies of your parent's will, power of attorney and other important documents.
- Investigate home care, which can include nurses, therapists, housekeepers and personal care workers. Since home care is a provincial or territorial responsibility, eligibility and criteria vary widely. Call your provincial Health Department.

Red Flag Checklist

If you're a long-distance caregiver, how can you tell if your parent may need more care than is being provided? When you visit, watch for these danger signs.

- The fridge is nearly empty – or else it's full of moldy food – and your parent is losing weight.
- There are piles of unopened mail, unread newspapers and unpaid bills.
- You notice bruises that could be from a fall. Falls are a leading cause of death among the elderly.
- The house or apartment has not been cleaned in weeks.
- Your parent gives money away to every telemarketer or junk mail solicitor.
- Your parent becomes reclusive or fearful, indicating possible depression.
- Your parent shows serious signs of forgetfulness – not forgetting where the car keys are (we all do that), but forgetting what the car keys are for.



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If your parent can no longer perform the eight intermediate activities of daily living – shopping, preparing meals, keeping the house, doing laundry, using the phone, using transportation (either driving or taking public transit), taking medication and handling finances – services such as grocery delivery, Meals on Wheels, a cleaning person and an automatic bill-payment plan can help prolong your parent’s independence.

If your parent can no longer handle the six basic activities of daily living – eating, dressing, getting in and out of bed, getting to the bathroom, and continence – daily help is essential.