Who is caring for the CAREGIVERS?

Family members, usually women, are the main caregivers of a burgeoning population of elderly Canadians. They need respite, resources and government support for this full-time responsibility that challenges their own personal health | by Christine Langlois

Photography: George Doyle & Ciaran Griffin/Getty Images

On the promise of anonymity, my friend Virginia Lee* has spent 45 minutes on the phone with me, spilling her guts about her frustrations trying to help her 82-year-old father manage through several recent illnesses and the beginnings of memory loss. Often, she feels inadequate to the job but she does appreciate knowing she's not alone. "All my girlfriends are complaining that their parents are driving them crazy," she says. Indeed, raise the topic of caring for parents at any gathering of 50- and 60-year-olds, and stories burst out of people in an angry torrent.

The stories are usually about a lumbering health-care system that, in spite of endless rounds of doctors' appointments and hospital visits, is struggling to meet the needs of the frail elderly with multiple health problems, about family members who can't agree about the best way to help, about parents themselves who refuse the help that's offered. And always the underlying theme is that just as soon as one problem is solved, another crisis looms. Lee, who, at 53, is an office manager and mother of two teenagers, describes it this way: "What it does to me is that I can't seem to focus. I'm always worried. It takes me off my game. I think, 'Things are okay now, but what about next week?'"

Caring for elderly parents in their last years is an inevitable part of the cycle of life, and today's boomers are taking their turn. But what's different today is that people are living much longer, often with many overlapping problems. "People are caring for the frail elderly who in the past would have died," says Robert Glossop, senior research associate at the Vanier Institute of the Family in Ottawa. And the generation who is caring for them are mostly women in the workforce with a range of other responsibilities, sometimes including active parenting.

** Names have been changed*

The population of seniors over 80 has increased dramatically in recent years. Statistics Canada figures show a 40 per cent increase from 1991 to 2001, and much more growth expected. During the same time period, we've seen a major shift away from institutional care for the elderly to care in the community. And the main source of that care is family members, increasingly supplemented by formal care in the community as a senior ages.

Lee's father doesn't yet receive any ongoing formal care. A retired engineer, he still lives in his Toronto condo and makes regular trips to Mexico. But a major heart attack and other related ailments have forced him into hospital for several long stays in the last three years. Lee and her three siblings take turns accompanying him to medical appointments, keeping track of what is (or most often isn't) in his fridge, checking to make sure he gets to where he says he's going. It's "management by crisis," she says. Sometimes, the crisis is a full-blown medical emergency with the siblings spending many hours monitoring their father's care in hospital; sometimes, a crisis is the result of poor communication and confused expectations. As an example, recently her dad had to go into hospital for day surgery. Her brother took time off work to get him there but didn't understand (or agree) that he should stay with him. He dropped his father off and planned to come back to pick him up. But the surgery was cancelled so Dad went home by subway without remembering to call anyone. First, there was a surreal search through several hospital departments looking for him. Then angry phone calls among the siblings about what had happened. One sister, in particular, feels very strongly that one of them should accompany their father to all medical appointments and procedures. "It creates a lot of tension," Lee says.

Caring for a frail elderly parent can bring siblings closer together or it can fracture their relationships, says Ingrid Connidis, a professor of sociology at the University of Western Ontario in London, Ont., and author of the book *Family Ties and Aging*. Most families do a good job of sharing the labour, with adult children who live nearest to elderly parents taking on most of the work and daughters taking on more responsibility than sons. Adult children who live farther away, who have younger children or who don't have the financial means to help are seen to have "legitimate excuses" not to be as involved, she says. In families where siblings and parents care for each other, those excuses are much more likely to be accepted than in families where tension already exists.

When one sibling feels overburdened, it creates animosity that can result in the family drifting apart, especially after the parents die. "When there is conflict among survivors, families can break apart. The older generation is the centrepiece of everyone's affection," says Robert Glossop.

Lee, like most adult children providing care, finds her responsibilities eat into her workday and often leave her distracted. Linda Duxbury, a professor in the Sprott School of Business at Carleton University who has studied work-family balance, says the lack of support for caregivers is taking its toll. Her research shows only four per cent of employees have access to any kind of eldercare support through employers. She suggests employers will need to improve or face losing staff. The current worker shortage is giving employees a choice, and many are choosing to take early retirement or work part-time or move to a more flexible company to have the time to care for their parents. "Companies are going to lose a productive cadre of workers," she says.

Many of the workers now caring for frail parents were caring for their children in the '80s and '90s when there was only minimal corporate support to help employees balance their work and family responsibilities. "At that time, employees just had to suck it up. Now, they're saying I'm not prepared to do it any more," Duxbury says.

Duxbury sees the need for more government and corporate help. "We need a national eldercare program," she says. In particular, families need help with crisis intervention. When a senior breaks a hip, for example, she often needs care for many weeks before she can manage at home again. Currently, home care is inadequate in most parts of the country, and families face long waiting lists for respite care in long-term care facilities.

Recently, families in one Canadian city faced the terrible choice of either paying huge fees or having an elderly parent in long-term care in hospital moved hundreds of miles away. Kingston General Hospital had such a serious bed shortage that it began charging long-term care patients $800 a day if they refused to accept a similar bed elsewhere in the province.

Negotiating placing a parent into long-term care permanently is probably the most difficult step adult children make. And often it's a decision that must be made quickly and during a crisis. Sherri Auger, as an only child, had no one to turn to when both her parents became sick at the same time. First, her 80-year-old father was hospitalized with liver problems, then her mother, 78, with heart disease, which would prove fatal. Although the two of them had been managing quite well at home together, her dad couldn't carry on alone. "One day, I had to make the decision to put my dad into long-term care. The next morning, I had to make the decision to take my mother off life support," she remembers. Her experiences led Auger to start her own business helping families manage eldercare decisions. She counsels her clients to let go of their guilt, which can be overwhelming. There comes a time when "you have to take responsibility for your parents," she says.

Adult children dealing with these kinds of eldercare issues will find little support from their employers. However, other kinds of

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help may be on the way. The first backup eldercare program launched in Canada in January when daycare provider Kids & Company opened its site in Calgary. The program offers eldercare by the day, week or month. CEO Victoria Sopik says the idea came from the human resources people she meets with regularly to discuss daycare trends who told her their employees needed help caring for their parents too. Kids & Company partnered with an assisted living centre that is home to 170 seniors. The seniors who attend the eldercare program have access to the hair salon, craft room, Internet café. The program will benefit employees who need a break. One senior executive whose elderly mother lives with her and her young family was thrilled at the prospect of the service. She wanted to plan a holiday with her kids to Disney World but couldn't leave her mother alone or take her with the family. "Now, her mom will come to the program while the family is away," Sopik says.

While we're often quick to make the leap from child care to eldercare, the two responsibilities are very different. "The end point of caring for an elderly parent is that they may become more demented and they eventually die. Hope is not there," says Robert Glossop. One of the hallmarks of eldercare is its unpredictability. While the needs of children can be linked to their age, the same is not true for the elderly. Most two-year-olds have similar needs, but the same can't be said for 82-year-olds. And while children live with their parents, an elderly parent may live in the same home, nearby or halfway around the world. And then there's the elderly parent-adult child relationship itself, which is often fraught with tension. Usually, it's the adult child offering help and the aging parent resisting. In a society where we put a high premium on autonomy and individuality, "it's very difficult and emotional to acknowledge any kind of dependency," Glossop says.

Mary Ellen Tomlinson, who has a small agency that assists people with eldercare, says the biggest stumbling block to helping the frail elderly is their own resistance. "Most won't accept it – it's an assault to their ego. They have been brought up to be self-supporting and self-sufficient."

Maggie Sanderson*, 55, is in the frustrating position of trying to help her 81-year-old father who doesn't want to be helped. Recently left incontinent after prostate surgery, he's having trouble managing his catheter and isn't eating or taking his heart medications regularly. On good days, he manages to get dressed and do a few errands, but on bad days he stays in bed. Living alone in the family home in a small community north of Ottawa, he refuses offers of assistance with upkeep with the result that several of his appliances need repairs. His bathroom ceiling is ripped open where he tried to find a leak. The house needs a major cleaning with most surfaces covered with junk mail and misplaced household items. And he's having difficulty managing his finances. "We've offered to do the repairs on the house or to help him move into a senior's apartment, but he refuses. He keeps saying he can do it himself but he can't."

"He's very angry that he can't manage his life the way he used to," she says. Her dad is slowly accepting personal care at home. He does have the VON come in and, after sending a personal service

AS THE NEEDS OF ELDERLY PARENTS HAVE INCREASED, COMPANIES HAVE SPRUNG UP TO OFFER SUPPORT TO CAREGIVERS. HERE'S ADVICE FROM TWO OF THEM

Mary Ellen Tomlinson owns Senior Care Options in Toronto. She co-ordinates care for the frail elderly at the request of adult children and offers workshops on eldercare to corporations. In her workshop entitled Take the Chaos out of Caregiving, she urges adult children to think through their parents' needs and to plan ahead for almost inevitable crises that will develop. One piece of advice is that anyone with caregiving responsibilities have a list of phone numbers and information with them at all times that includes their parent's doctor, nearest hospital, lists of parent's medications. That way, when a parent has a medical emergency, the caregiver can manage the crisis at a distance for a period of time until she can leave her workplace and get to the hospital.

Peter Silin, who owns Diamond Geriatrics in Vancouver, also encourages clients to plan ahead so that they know what services are available to their parents in their community and their province so that they can quickly "get up to speed" when a crisis occurs.

Silin's second piece of advice is to learn as much as possible about the processes of aging, particularly about how memory loss occurs. Memory loss and signs of cognitive impairment can be the result of some form of dementia, such as Alzheimer's disease, which is irreversible. It can also be a symptom of depression or delirium caused by a urinary tract infection or over-medication, which can be reversible.

Don't just assume that memory loss and confusion are inevitable signs of getting older, Silin says. An elderly person showing signs of cognitive impairment should see a doctor for a physical exam that includes blood tests and urinalysis and have their medication assessed to be sure he isn't over-medicating or taking his medications at the wrong time. "The first thing I ask adult children is, 'Has your parent been to the doctor and had a full exam?'" Silin says.

worker away a few times, he now lets her in the house. "It's always two steps forward, one step back," Sanderson says. Her dad's behaviour has become more reckless, and he's showing poor judgment – he recently got a speeding ticket and had a minor car accident – but he's not suffering from any obvious memory impairment. "He gets overwhelmed by his physical ailments and daily activities of life, but he can't seem to understand that getting help with repairs or his meals and laundry would help him cope," she says. The two have had several ugly arguments recently over Sanderson's safety concerns, and Sanderson is at the end of her rope. "I feel like I'm spending so much time worrying about him and trying to figure out how to help him. I'm feeling quite resentful and angry myself." Sanderson is a self-employed accountant. "I have to plan my schedule carefully to take time off – every day I spend dealing with some crisis with my dad is a day away from the business." Luckily, other siblings are helping too. "My brothers have started talking to him about his situation and offering help. Maybe they'll get through to him," she says.

Katie Podniarski*, 61, talks about resentment too. After her father died, her mother, 88, decided she wanted to move from the family home into the senior's apartment they'd planned to live in together. But the move didn't go well. Her mother was grieving and seriously depressed. "I'd go to visit her, and she'd be sitting alone in the apartment in the dark. She wouldn't have changed her clothes for days." Her mother lived three hours away, and Podniarski was constantly travelling back and forth trying to arrange for care and keep her mom company. "Long-distance caregiving was going to be the end of me," she says. Podniarski finally convinced her mom to move from her small town to a private assisted-living facility near Podniarski's home in Montreal. And she promised that if her mom moved, she'd visit her every day. So now Podniarski, who is divorced and has a senior management position in an insurance company, visits her mom every evening, manages her deteriorating health, does her laundry and take her our on weekends.

But with their declining birth rate, boomers have fewer offspring. Anyone who really doesn't want to be a burden to their kids in 20 years needs to plan ahead how to negotiate their final years

"I'm really proud of her that she made the move and has adjusted," she says. "I told her that if she made this move, it would prolong her life – and it has." But at the same time, she's resentful of the amount of time her mom needs. When she made her promise of a daily visit, she expected to do it for a few months until her mother settled in, but it's now going into her second year. Her mom understands when she tells her she can't come occasionally, but she knows her visit is the bright spot in her mom's day. Recently, Podniarski refused an extended business trip that would have taken her to Asia for two weeks. "I know she's being cared for, but she would really miss me," she says.

When Podniarski's mother was in her 60s as Podniarski is now, she and her husband enjoyed their retirement travelling the world. Free of responsibility for either children or elders, "they had the time of their lives," Podniarski says. "Sometimes I want to remind my mother of that."

It's not all negative. Podniarski is enjoying the time she spends with her mom and is happy she can make such a difference in her final years. "My goal is to make sure that my mother ends her last years as comfortably and happily as possible," she says. Never close before, they have now forged a much stronger relationship. Recently, her mom told her a family secret that she'd never shared with anyone. And they have lots of laughs at the role reversal that has occurred between them. Podniarski often has to remind her mother to take her cane with her or to use her walker. She'll say, "Mom, it's for your own good," because that's what her mom said so often to her when she was growing up.

Boomers who are currently caring for frail elderly parents may feel overburdened, but that's nothing to how their kids will feel when it becomes their turn, says Ingrid Connidis, professor of sociology at University of Western Ontario in London, Ont. She points out that the large number of boomers means the responsibility is shared. "Right now, we have a large cohort looking after a small one." But with their declining birth rate, boomers have fewer offspring. Anyone who really doesn't want to be a burden to their kids in 20 years needs to plan ahead how to negotiate their final years. ●

CALLING ALL HEARTS

The University Health Network needs volunteers with big hearts and helping hands. The cardiac visiting program at Toronto General Hospital is designed to bring together current cardiac surgery patients with volunteers who have undergone cardiac surgery in the past. Volunteers talk with cardiac patients at least once before surgery and at least once afterward, helping to reduce anxiety by explaining what to expect and providing an emotional safe place for all involved.

Minimum commitment of six months and one four-hour shift a week. Contact Lisa Ripper, Specialist, Volunteer Recruitment at University Health Network: 416-340-4800 ext 8174 or go to www.uhn.ca.