



SANDWICHED CAREGIVERS

BY CHERYL MAHAFFY

A growing number of Albertans look after their children and also their own aging parents. Who looks after them?

FOR YEARS, I'VE KNOWN TERESE BRASEN AS A TALENTED and creative writer. But in a huge other part of her life, she's a sandwiched caregiver. That is, she looks after not only her children, but her parents. It's a reality she doesn't often mention to clients, not wanting to raise the spectre of unmet deadlines. But as her parents age and lose their independence, she's increasingly consumed by their care.

As we walk through the sunlight of a beautiful Edmonton day, Brasen tells me of her latest caregiving crisis. After rushing home that evening from a marathon curriculum planning session at Grant MacEwan College, she telephoned her father's apartment across the street to check if he'd managed supper without her. He didn't answer. The 84-year-old had gone for a walk, fallen, been scooped into an ambulance and ended up at the Grey Nuns Hospital. Because he was incoherent, medical staff assumed he was an alcoholic.

Alcoholic. The label hit Brasen in the gut, clashing as it did with her growing-up experience of a father who stood out in a crowd as well dressed and well spoken. His confusion actually reflected advancing dementia, lack of food, and complications of recent heart surgery, she says. "My dad has never been drunk in his life. It showed me that if you're in the system and you don't have anybody advocating for you, people can make assumptions that are very, very incorrect."

For Brasen, this latest hospitalization was yet another low point in an intense rollercoaster ride that began years ago as her father struggled to remain independent while mental illness stalked her mother. Brasen has been there for each hospitalization, each of her parents' shifts to increasing dependence, each attempt to make a rule-bound system meet her parents' needs, all while raising two sons, now ages 11 and 18.

It is taking its toll.

"Like many women of my generation, I had my kids late—and my mother also had her kids late," Brasen says. "So here I am at this stage where I should really be looking after myself, and instead I'm caring for these two generations who depend on me. My father is becoming more and more childlike. My youngest is becoming a teen. It's like living in a war zone, and you can't stop taking care of it... but how long can it go on?"

Brasen's situation is increasingly common, says Janet Fast, who with Norah Keating heads a research on aging policies and

practices unit at the University of Alberta. With the bulge of baby boomers aging and life expectancy increasing, one in five Canadians will be 65 or older by 2026. Two-thirds of seniors 75 and older depend on family and friends for help, and with fertility rates declining, that help is spread among fewer offspring. "The average married couple may have more living parents than children," notes Cara Williams of Statistics Canada, in a report based on the 2002 General Social Survey (GSS).

When their parents reach a critical stage with their health, a growing number of Albertans have their own children still living at home. For those children, close contact with grandparents can be enriching. "My father can remember when the radio was invented. Not the television, the radio," says Brasen, whose sons have formed a warm bond with their grandfather over the years. But as numerous caregivers attest, kids also deal with the downsides: bathroom messes, botched holiday plans, short tempers—and always, not enough time.

Time is a huge issue, and it's exacerbated by the marked increase in women working for pay, leaving no one home full time. "Trouble is, we're all overachievers," Brasen says of her siblings. "We're not people who've really developed the skill of having a lot of leisure time." Many others could say the same. Fully 83 per cent of sandwiched caregivers in the 2002 GSS were employed.

As a result, many caregivers "are thinly spread," Williams reports in the summer 2005 *Canadian Social Trends*. What's more, she adds, "while parents have seen childcare services evolve, little formal support has been established for the growing number of middle-aged men and women caring for seniors."

Terese Brasen is far from alone in feeling overwhelmed. According to the 2002 GSS, 76 per cent of sandwiched caregivers providing high intensity care (defined as more than eight hours a month) feel stressed. More than half reported extra expenses and changed social activities. One in three shifted their work hours; one in four worked less; one in six lived on reduced income. One in five reported changed sleep patterns and impact on their own health.

Despite this, 95 per cent of sandwiched caregivers surveyed said they felt satisfied with life. Most reported they were giving back what life had given them and nearly three-quarters said their caregiving resulted in a stronger relationship with those receiving care. In short, many sandwiched caregivers

Left: Terese Brasen (shown here with her father, Torben Rasmussen, and youngest son, Langston Brasen) is a sandwiched caregiver, caring for her children and her aging parents. Two-thirds of seniors 75 and older depend on family and friends for care.

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are stressed, yet at some level satisfied. That's not to say they wouldn't welcome stress relief.

Calgary's Christine Curran is a case in point. Four years ago, her mother-in-law, Elizabeth, came from Victoria for a Christmas visit that has extended to this day. "She refused to go home, and I just knew she was miserable," Curran says. "So I rented a U-Haul and moved her here."

Curran relishes her caregiving role. "I love my mother-in-law. We were always friends," she says. "Something that's always been noted in our relationship is that I'm a caregiver and she's needy. She clings to me and I love giving care, so it's perfect."

Yet the journey has been anything but easy. Elizabeth regressed rapidly from living with the family (and insisting on daily shopping binges), to attempting independent life (and dangerously self-medicating), to placement in a dementia unit at Calgary's Beverly Centre. "Even now, I go every single day," Curran says. "And when she was independent, she would have drugged herself if I hadn't spent most of my days with her. What happens to people whose caregivers work? She would have been dead."

"It's a very stressful situation. Very stressful," Curran says. "I didn't know anything about taking care of seniors." Despite varying degrees of support from friends, a sister-in-law, two teenage sons and a husband whose job often takes him away from home, Curran feels the weight of being in charge.

Indeed, as with childcare responsibilities, women bear the brunt of senior care. Women in the 2002 GSS reported doing twice as much eldercare as men. What's more, women said they did nearly 80 per cent of the intense personal care, while men concentrated on outside chores and transportation.

Pam Weir shouldered the lion's share of mother-in-law Dorothy's care for 2 1/2 years—without the satisfaction of seeing Dorothy thrive. "It was totally on my shoulders, and that was the difficult part," says the Edmonton mother of five, who also educates her two youngest at home and operates a home-based nutritional supplement business.

With an urgency common among caregivers, Weir describes day after day of "24/7" care for a woman whose every attempt to be less of a burden added to the stress. Dorothy refused to get out of bed in an attempt to stay out of the way, then would often be up all night. Looking for ways to help despite advancing Alzheimer's, Dorothy would offer to fold laundry then leave it scattered about for days, adding to the cyclone effect that forced Weir to curtail business visits. Despite it all, Dorothy wasn't happy.

"Oh, I don't know why old people live so long," she'd say.

"I was setting up a situation where she could be happy, but she chose to not be happy," Weir says. "And so I was beating myself up." By month 19, she says, "I was in tears all the time." After 10 more agonizing months, it was clear something had to change. "My husband said, 'You can't do this anymore. You have done enough for her, and I can't watch you destroy yourself. So we have to make other arrangements.' And I'm thankful he did."

Yet Weir is glad her two youngest experienced life with their grandmother for awhile. She recalls how they learned of their heritage through her stories, how daughter Val played Sorry with her grandma for hours on end, how Grandma and son Ian shared bantering word play. "I sometimes would feel like it wasn't fair to them, and yet I really believe it has enriched their lives and their perspective," she says. Ian has since begun to volunteer with seniors, she says. "They have a compassion that most young people nowadays don't have."

Like many, Weir's caregiving began so suddenly that she had no inkling of the supports available, and it struck with such intensity that she lacked the time or energy to hunt for help. Not until she phoned a mental health line in sobbing desperation did opportunities for respite, home care and appropriate housing surface. "I said, 'Tell me step by step what I need to do.' When I asked that question, they were really good at stepping me through. But how long did I live without even knowing what was available?"

Even when seniors enter a hospital or care facility, information about available options is spotty at best, as Terri Harris found. Harris was pregnant with her third child when her mother suffered a cerebral hemorrhage that left her paralyzed on one side and unable to speak. "She lived beside us and all along she was going to be my caregiver, so when this happened it just threw our plans right out the door," Harris says. Suddenly unable to predict beyond tomorrow, the extended family focused instead on making the best possible choices for a mother who, at age 69, could live for years—or not.

At first the family felt almost like pioneers, Harris says, "like mom was the only person who went through this." They were unhappy with the options offered in various Calgary-area facilities their mother passed through, and they started surfing the Internet. There they discovered both appropriate programs and people who, having walked the same road, could cheer them on. "They were telling us 'What you're doing for your mom is great—just great. You have to be your mom's advocate. Push for what you want.'"

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Accessing services can be even more difficult when the sandwiched caregivers are immigrants. In fact, any issue faced by sandwiched caregivers becomes more acute in immigrant and refugee families. That reality strikes Zdravka Brnada and Jalal Barzangi every day as they reach out to isolated seniors through a small action research project spearheaded by Edmonton's Multicultural Health Brokers Co-op.

Many sandwiched newcomers are barely scraping by, Brnada and Barzangi say, and each generation is getting squeezed. Often, grandparents are sponsored by their children, and immigration law makes sponsors solely responsible for the grandparents' first decade in the country. "So parents are a financial burden on their kids, and they feel a huge pressure," Brnada says. "Families are overwhelmed by struggling to survive, often working two or more low-paying jobs. And 10 years is a long time."

Language barriers also challenge these homes. "Often grandparents cannot communicate with their grandchildren, which is very sad," Brnada says. In other cases, only the youngest generation speaks both languages, and preteens are enlisted to interpret and even advocate for the family, with understandably limited success. Even parents who can speak English lack the time to scout out resources that might ease their situation.

Realizing that many seniors she serves don't take advantage of home care, one of the few benefits available during the 10-year sponsorship period, Brnada has helped numerous families apply. At the same time, she urges agencies to send workers who know her clients' language to help counter the isolation they feel in a foreign land. "Not only do we need to help immigrant seniors," she says, "but we also need to help mainstream agencies understand the differences those seniors face."

WHY DOES THE CAREGIVER'S LABOUR OF LOVE SO OFTEN become a hellish experience? There's no doubt that taking care of both parents and children is a complex and delicate task, with each situation unique. Even so, couldn't more be done to make it work?

Certainly, says Diana McIntyre, president of the Edmonton-based Alberta Caregivers Association (ACA). The exhausting and isolating experience of caring for a husband with Alzheimer's prompted her to launch the ACA four years ago.

Canada falls considerably behind Britain and Australia and even the US in legislating support for caregivers, McIntyre says. Nor do support groups for conditions such as Parkinson's, multiple sclerosis and Alzheimer's focus on caregiver needs. "We

talked to many caregivers when starting this organization, and there were a multitude of cases where the caregiver ultimately had a breakdown. Others were telling us the stress required them to put the person they were caring for in a long-term facility, whereas with support from the beginning they would have been able to continue longer."

Family caregiving requires two key ingredients to succeed, says ACA program director Giri Puligandla: self care and community support. "Using the analogy of the oxygen mask in an airplane, if you can't breathe, how are you going to help another person breathe? Secondly, the community at large has to recognize the caregivers' sacrifices and help them. Not just saying 'Give me a call if you need help,' but 'I'll come over and spend time with the person. Why don't you get a haircut or go for coffee?'"

Beyond relying on the person next door, the ACA envisions a time when community support will be recognized in public policy, ensuring families receive what they need to function as an essential part of the caregiving team. "The government has made some great strides over the last few decades toward recognizing the patients' place in determining how they receive treatment," Puligandla says. "Now we have to move beyond that—we have to move to the family-centered approach. Because really, when we're dealing with an illness we're dealing with the whole family."

Alberta already has two innovative programs that could be models of support systems for families caring for aging parents, ACA leaders say. Family Support for Children with Disabilities provides respite, compensation for out-of-pocket costs and other necessities for at-home care of children with disabilities. The Alberta Brain Injury Initiative provides a province-wide network of service coordinators for adults with acquired brain injury. "Since we have these good frameworks, there's no reason we shouldn't apply them to other situations where there is need," Puligandla says.

At the federal level, two programs offer what the U of A's Janet Fast calls "marginal" relief to a subset of family caregivers. Those with relatives near death can apply for up to six weeks' partial salary and up to eight weeks' job protection. (In Alberta, this applies only to employees of federally regulated industries.) Lower income families providing in-home care can receive up to \$600 in federal tax credit.

Neither program compensates for the "big economic hit" taken by caregiving families, Fast says. Many give up jobs, forgo promotions, purchase equipment, buy medications, top up care—and in the long term, receive less retirement income. "Those

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economic consequences, combined with consequences for the caregivers' own health, are creating our sick, poor seniors of the future," says Fast.

Caregivers can tap some supports, at least in urban areas. Respite beds and day programs, for example, offer breaks that are particularly crucial for those caring for someone with dementia or Alzheimer's. But respite must be booked months in advance, and day programs serve the care receiver, leaving caregivers to schedule life around pickup and drop-off times.

Similarly, home care can be a lifesaver for those who need help with bathing, feeding and other necessities. But as Brasen discovered, besides being uneven in quality, the care is often too little, too late. "The message was 'because you're there doing this, he's just fine.' But I'm doing this because he's not fine," says Brasen. "It's almost like you have to pull your finger out of the dike to get some help, so it always ends up in a crisis."

Sandwiched families pay the price for the fact that patients are released from hospital quicker and sicker, Fast says. The new reality of hospital care spreads home care resources thinner and thinner. "Home care's original clientele were those who had chronic care needs. But [home care resources have] been diverted to people going home from acute care institutions who still need a fairly high level of care, such as medications and intravenous therapy," says Fast. Policy makers worry about the cost of expanding home care, she adds, but her group's research suggests that an appropriate amount of formal help often enables families and friends to provide substantially more care themselves.

For caregivers near Calgary and Edmonton, support centres are popping up—places to vent and learn from each other's experiences (see the seniors services guide starting on page 48). Calgary Health Region's Family Caregiver Centre regularly pulls families from the brink of despair through a combination of information, education and supportive counselling. In Edmonton, caregivers can turn to such resources as the ACA, a new Eldercare Academy at NorQuest College and a support group at the Society for the Retired and Semi-Retired. Caregivers in other parts of the province have fewer options, although the ACA is eager to assist any who wish to form local support groups.

Peer support is invaluable because it offers empathy, not sympathy, says Pam Weir, who attends the Society for the Retired and Semi-Retired group. She recalls how friends' sympathetic "I don't know how you do it" fuelled her self-doubts. "That was when I really started to go downhill, because I began to think

I was trying to do something superhuman." Fellow caregivers, by contrast, prove that looking after your own is feasible—with help. "Sometimes it's just having somebody there give you a hug and say 'have you tried this?' It gives you hope."

FOR BETTER OR WORSE, NONE OF THE SENIORS WHOSE caregivers were interviewed for this story live at home today. Some have died. Others are in care centres. Particularly for those with dementia or Alzheimer's, whose care is extremely taxing, perhaps that's where they need to be. "Home is not always the best place," says Roger Breault, whose mother-in-law gained welcome weight in a seniors' home. "If we had known more, we would have moved her there earlier."

No matter where the senior lives, however, the need for care—or at least vigilance—continues, to ensure harried staff provide adequate care. Nor do emotions diminish. In addition to the guilt many feel at placing a parent in an institution, there's grief as parents' abilities ebb away. Christine Curran's mother-in-law suddenly became incontinent a few months ago, greatly curtailing their ability to go out together. Terri Harris's mom shows no sign of recognizing the grandchild born after her brain injury. Terese Brasen's father continues to lose his mental capacity, amplifying what she calls a bizarre role reversal.

Accepting this reversal is key to healthy caregiving, says the ACA's Puligandla. "It takes a lot of soul searching and thought and emotional catharsis, but once caregivers reach that point [of acceptance] it's like a rebirth. Suddenly it's positive and okay to look after their own needs rather than getting sucked completely into the caregiving role."

With her father settled in the same care centre that already houses her mother, Brasen has the breathing space to ponder what caregiving has told her about life—and particularly about her own senior years. "It has made me extremely health conscious. If I live long, I want to be strong and healthy," she tells me. "It has also made me very social. I don't want to rely on my children. I intend to stay in close contact with my friends and to help them when they are old. I hope someone will also be there to help me."

Cheryl Mahaffy has written for *Alberta Views*, *Legacy*, *Homemaker's*, *Alberta Venture* and numerous newspapers. She is working on a book entitled *Women Building Alberta*, about female architects.