

THIS DAY  
IS FOR *Me* 

**Caring for the caregivers**

by Silver Donald Cameron

**THE J.W. McCONNELL  
FAMILY FOUNDATION**

The J.W. McConnell Family Foundation  
1002 Sherbrooke Street West, Suite 1800  
Montréal, Québec  
H3A 3L6  
Tel.: (514) 288-2133  
Fax: (514) 288-1479  
E-mail: [inquiries@mcconnellfoundation.ca](mailto:inquiries@mcconnellfoundation.ca)  
[www.mcconnellfoundation.ca](http://www.mcconnellfoundation.ca)

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# Preface

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Looking after a spouse, family member or friend who is ill or disabled occupies an increasing number of Canadians; the need to do so one day is something we all must envisage. In fact caregiving, most often by family members, is the invisible back-up that allows our health care system to keep functioning as it continues to shift away from institutionalized care. But our health and social services systems are woefully inadequate in even recognizing, let alone assisting, caregivers.

In 1999 the McConnell Foundation approved eight three-year proposals to test different forms of support that have the potential to significantly ease the lives of family caregivers. The projects built on the 1998 findings of the Canadian Association for Community Care (CACC) National Respite Care project that addressed the critical and growing need for flexible respite. The CACC concluded that “respite should be seen as the outcome derived by the caregiver as a result of being given either time off from caregiving duties, or direct support for his/her needs... Respite is the break/time off/relief *experienced by the caregiver*, not the replacement service provided to the care recipient.”

While many caregivers themselves are looking for respite in its broadest sense, the concept of respite as a *result* of varied interventions challenges providers to move beyond thinking in terms of a set of fixed services, toward a more individually tailored, flexible and ultimately more effective response.

Silver Donald Cameron, a former caregiver himself, eloquently describes the caregiving experience, how these eight projects have tried to address respite differently, and why it is critically important for all levels of Canadian society to recognize and support the caregivers in our midst.

Tim Brodhead, President and CEO  
The J.W. McConnell Family Foundation



# *A Pilot and a Caregiver*

I am introduced to him at an adult daycare centre operated by the Victorian Order of Nurses—a tall, stooped man of 78, with a well-trimmed moustache and a manner still marked by military discipline. He has almost a courtly politeness, but he is preoccupied. Meeting me is not an important occasion in his day. With half a dozen other elderly men and women, he is watching a vapid television program. He dislikes the interruption.

Sixty years ago, he was the man I hungered to become. I was a young boy then, growing up in a world gone mad, bombs and artillery thundering in Europe and Asia, ships being torpedoed within sight of Halifax, Vera Lynn singing about the white cliffs of Dover.

And this man, at 19, was a British fighter pilot with a bronzed face, quicksilver reflexes, steely nerves and a will of iron. He was an authentic hero, flying out over the English Channel every day with machine guns in his wings and a song in his heart, doing perilous solo combat with an indisputably evil empire.

A whole industry, blended of culture and propaganda, celebrated these deadly acrobats of the air. One Saturday afternoon I sat twice through a fighter-pilot film called *Wings for the Eagle*, until my name appeared on the screen: DONALD CAMERON, GO HOME. I thought God

had caught me, and was grateful that it was simply the result of a phone call from my worried parents. I still have my copy of *Sky Attack*, one of eight thrilling young-adult novels by Canfield Cook about a pilot named Bob “Lucky” Terrell. I would have given anything to be a Spitfire pilot for just one day.

They were really the last of the knights errant, those pilots, and an anachronism even then. War was already an expression of mass society, technological and managerial, a conflict of vast fleets and armies organized and directed by distant executives. The duelists who flew the Spitfires and Hurricanes were the only warriors in modern times to engage the enemy one-on-one in single-handed battle.

Today good and evil are confounded. Our heroes are flawed, our villains had unhappy childhoods. My hero is your monster. Searching for unalloyed evils to vanquish, we find only Star Wars films and video games. But the fighter pilots were unambiguous, and they had no critics. For a brief moment, the fate of civilization really was in their hands.

Now this lord of the skies, who once flew free through three dimensions of air, has been captured by an invisible enemy called Alzheimer’s disease. He sits in a day-care centre, trapped in the collapsing corridors of his decaying consciousness.

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This is a good time to visit his wife, who cares for him in their modest bungalow. She has peppered the house with little notes, reminding him of the day and the date, when the garbage is collected, phone numbers of physicians and friends and family. A sign near the phone sternly warns NOT to purchase ANYTHING over the phone.

A set of living-room curtains conceal the front door, so he won't be tempted to go out. All the doors have had alarm bells ever since the night he was found wandering the streets of this little town, heading for the airbase from which he retired years ago. Folding gates guard all the stairs. She has to be constantly alert and ready to help him. The hands which once held the joystick of a Spitfire now can't remember whether to pull the underpants on before the trousers, or vice-versa. The pilot is not even allowed to drive any more. Sometimes he just wanders out to the driveway and stands looking wistfully at the car.

But this afternoon, with her husband in day-care, is a period of respite.

"I like today," she says. "This day is for me."

At 76, she is still pretty, and she laughs as she remembers how she met her husband. She received a letter, she says, in which he revealed that he had seen her walking across a hangar, and wished to

make her acquaintance. Both were then working for British Airways in Bristol. They were married in 1953. But then, after the war, British Airways moved to London, and they didn't want to live in London. The Royal Canadian Air Force was recruiting, and her husband joined up again. The RCAF posted them to France first, and they emigrated to Canada in 1955.

Wait, now. They were married in 1953, and moved to London "after the war." Yes, she smiles, that's right. But it isn't. It can't be. Something clicks: she isn't just vague. She's badly confused.

The notes on the walls are for her as much as for him. And who will care for her as her memory slips away, this woman whose life is already devoted to caring for her husband?



# Caregiving and Respite

If Canada's health-care system were a plant, family caregivers would be its roots—fragile, vital and invisible. The part we see—branches, leaves and flowers—is the apparatus of doctors, nurses, clinics, labs and hospitals. But the “visible” health-care system has always been supplemented by the invisible support of home caregivers. We rely more heavily on those caregivers with every passing year. We do very little to provide them with support, recognition or respite.

This is the story of a pilot program designed to explore the meaning and significance of respite for such caregivers—not as an intellectual exercise, but in practical form, out in the field, providing genuine respite to actual caregivers from coast to coast.

The program grew from a 1998 report on a national respite care project by the Canadian Association for Community Care. The most important conclusion of the CACC project challenged our very understanding of the nature of respite.

It suggested for example that respite is not the adult daycare service provided to the former pilot, but the relief experienced by his wife—the sense that “this day is for me.” The adult daycare service would not be the only possible way to provide that relief; it could have been provided by a substitute caregiver in the home, or by a family member

taking the husband for an afternoon drive, or even by a sleeping pill which would help him get some much needed sleep for four or five hours. The respite is not the mechanism which gives her the afternoon for herself; it is the experience of having the afternoon off—or, more broadly, the experience of relief.

Not every caregiver would want respite in precisely this form, however. For someone coping with a different set of disorders, relief might take the form of a completely different experience. The key element is that respite is determined by the caregiver's “voice and choice.”

In 1999, following up on the issue, the Foundation issued a call for proposals for projects which would test various approaches to providing “respite as outcome,” and which would document, evaluate and disseminate the findings, making their insights available to caregivers and family service organizations across the country.

The eight successful applicants took very different approaches to the task. Before describing the eight projects, however, we need to understand the concrete human problem—the daily experience of family caregivers.

# Health-Care System

The invisible health-care system is at work in every family, all the time. Most routine minor injuries and illnesses do not involve the visible medical establishment at all. Family members bandage one another's wounds, take one another's temperatures, carry meals to the bedside, care for one another as required. For more serious illnesses, we visit the doctor and perhaps spend a short period in hospital. For really serious illnesses, periods of hospital treatment alternate with long periods of convalescence at home. Very few conditions, even chronic or terminal ones, require prolonged hospitalization—and even then, family caregivers are a constant presence in the hospital room.

Most Canadians take this situation so much for granted that they scarcely think about it. In recent years, however, the "official" health care system has changed, moving towards shorter periods of hospitalization, more integration of the disabled into the community, more specialists, and fewer family practitioners. Those changes save money for the visible health-care system, but they do not reduce the total workload of Canadian health care. Instead, they shift the burden of caring for the sick, the dying, and the disabled onto friends, community and family—and disproportionately onto women.

And while doctors and nurses choose their own professions, most caregivers do not volunteer for an

unplanned life of service which may last for many years. In almost every case, caregivers are thrust into the role by unexpected circumstances—a newborn baby with multiple health problems, a spouse with a debilitating illness, an ageing parent with a wasting disease. Very often they have no training, no experience, and perhaps even no particular desire to nurse a loved one. They do it because there is no real alternative.

The demands of caregiving vary enormously from one situation to the next. Some caregivers only have to pay a daily visit, do the shopping, arrange for the evening meal. At the other end of the spectrum are caregivers who provide intense, round-the-clock care—administering medication several times daily (and nightly), changing bandages and diapers, giving injections, bathing and dressing and feeding, ferrying to and from appointments, conferring with doctors, negotiating with officials and agencies.

All caregivers are supposed to be able to do anything necessary. But they can't always do it.

"One caregiver's husband came home from the hospital, and she was told by the home care nurse that she'd have to give him regular injections," says Kim Pratt-Baker of the Seniors Resource Centre of Newfoundland and Labrador. "She said she couldn't, but was repeatedly urged to do so. They

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trained her and pressured her—but when the time came to give her husband the needle she passed out. Nobody had even asked her whether she was able to do this—they just made her feel guilty and badgered her into it.”

Chronic disabilities often seem to come in clusters. After 49 years of marriage, a woman finds herself caring for an insulin-dependent man who has been a diabetic for 30 years—and four years ago had a stroke. After that, the health problems cascaded down on him: trouble with his carotid artery, then quintuple by-pass surgery. Next he went into renal failure, and now depends on regular dialysis. As if that weren't enough, he also developed glaucoma, pulmonary fibrosis and nerve damage.

There are doctors who specialize in each of those conditions—but not in all of them together. The various disorders affect one another, and the array of symptoms is extremely confusing. The medication for one condition may cause problems with another. So the caregiver becomes the world's only expert on that particular constellation of disorders. She borrows books, searches the Web, talks to the specialists, and tries the different regimes of medication that are recommended to her.

In other cases, a single medical condition may itself be so rare that most doctors know virtually nothing about it. Few physicians are familiar with

a rare congenital neuromuscular disorder known as “nemaline rod myopathy” which produces extreme muscle weakness. It afflicts one person in six million—perhaps 50 or 60 people in all of North America.

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But for every such condition, there are probably a couple of researchers somewhere out there working on it. Typically, the caregiver will find those researchers, read their work, and talk with them on the phone. (Caregivers soon learn to be determined and insistent; their role requires it.) Maybe there's an association of people involved with the condition. Maybe some other caregiver has tried something that helped. If so, let's find that person. Over time, the caregiver comes to know a great deal about the condition, and becomes a resource for others. In a very real sense, the caregiver has to manage the illness on behalf of the patient.

And yet, despite the uniqueness of every situation, what caregivers have in common is the experience of putting someone else's needs ahead of their own, not occasionally or briefly, but constantly. You are famished, but she is in pain. You are stupefied by



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your need for sleep, but he needs his medication. You are depressed, but she is suicidal. Your bladder is bursting, but he suddenly has a seizure. Figure out what to do. Arrange to get it done. Then think about your own problem. The needs of the person you are caring for always come first.

You are nurse, cook, cleaner, chauffeur, counselor and comforter. If you are lucky, you have a strong relationship with the doctors, the physiotherapists, the dietitians, the home helpers, the neighbours and the family. If not, you become your family member's defender, navigator and advocate, insisting that the needs you can't meet must be met by others.

Your home changes, too. Once it was your castle, your private retreat. Now it is almost an institutional space—something between a prison and a hospital. You are rarely allowed to leave the house without arranging the conditions of your parole in advance. When you look around, you see the familiar family photos and mementoes—but you also see elevators, ramps, hospital beds, respirators, bed tables, medications, walkers and wheelchairs. Your home has become a strange environment, a building where treatment takes place.

Even your bedroom may not be private any more. The people who come and go through your home may be sensitive to your feelings about what was

once your private space—or they may not. They may leave their shoes on, make themselves refreshments or rearrange the furniture. Some have even been known to smoke without asking permission. They are not guests, but professionals. They are there to attend to the person you are caring for, and you can't risk alienating them. You need them. Your spouse or child or parent needs their help. But surely they could learn to wipe their feet and stop using language which offends you.

And in this strange place that was once your home, you have to continue with the necessary labour of daily life. You manage the household, write the cheques, answer the phone, do the washing, prepare the meals, and get the car repaired. But it takes three trips to complete the food shopping, because you have to keep returning home and checking on your charge's condition.

You may not even be able to go to a supermarket. You may have to go to a food bank instead. The added costs of care gradually eat away a family's savings, and support for the disabled and chronically ill is minimal at best; in some provinces it is shocking. A caregiver in one of these projects is caring for both a husband and a son with Huntington's disease, once known as "St. Vitus' Dance," a devastating, incurable, genetic disorder of the brain which slowly erodes the ability to walk, talk and even think. The son himself once had a wife and

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son, and the family had its own home and its own business. Now the two men are helpless—the father can barely speak—and the family survives on less than five hundred dollars a month.

The fundamental human relationships continue, even in terrible adversity. You still adore your wife, diminished though she is by the disease which confines her to a wheelchair. Your philandering husband still has a philandering brain. Your ailing mother may not remember what she had for breakfast, but she still doesn't think much of the man you married. Your child still thinks that Daddy can fix anything, including his withered leg.

You are a caregiver precisely because you have a deep and intimate relationship with the person you are looking after. Usually the bond is love, but not always. The bond may be one of obligation, religion or simply the lack of anyone else to do it. Perhaps you're the last child at home, and you know your father didn't want you and has never much cared for you. But now he's 99 years old, confused and child-like, and he has no place else to go. Will you walk away from his helplessness? It's unthinkable. And so the trap closes down over your life.

The ill and disabled remain real people, as unique and individual as they always were—funny, cranky, brave, fey, unreasonable, self-effacing, devout or impatient. But there is inevitably a power imbalance in the

relationship. The caregiver ultimately makes most decisions, even in couples who used to make decisions jointly, and the recipient has to accept them. But caregivers are not angels, either. The domineering husband, now bedridden, cannot stomp off in a huff, and the downtrodden wife may be forgiven if she sometimes takes advantage of that fact.

Caregiving often goes on for a long time—24 hours a day, 7 days a week, often for years, sometimes for decades. Kim Pratt-Baker of the Seniors Resource Centre of Newfoundland and Labrador found that for those who contacted the Centre's caregiver telephone line, the average length of a caregiver's service was nine years. For parents with children who are physically healthy but severely disabled in other ways, caregiving lasts a lifetime. Indeed, it may continue beyond the grave, as the parents attempt to ensure that their child will be cared for long after the parents have died.

You take it a day at a time, caregivers say. You don't make long-term plans, or even short-term ones. A day at a time, sometimes an hour at a time. The future—even the remainder of the day—is utterly beyond your control.

Caregivers frequently give up their jobs and lose their professions. Caregiving becomes, in effect, their career. Because they take so little care of themselves, their own health suffers. Since they can

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never do normal things—go to a movie, play cards, go for a walk—their friendships atrophy. And then, perhaps, the person they are looking after dies, and their caregiving career comes to an end. But caregiving was the whole content of their existence. Who are they now? And what are they to do with the rest of their lives?

In the meantime, their responsibilities fill their lives. What they need is respite. But what is respite?

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# *The Many Faces of Respite*

**R**espite is “being able to clean the house,” says Grace Auclair, whose five-year-old daughter Kristin is the one in six million born with nemaline rod myopathy. A bright little girl with a winning smile, Kristen is in a wheelchair, her breathing regulated by a machine, her food provided by a tube in her stomach. For four hours a week, Kristin is cared for by Isabelle, a volunteer from Montreal’s Le Phare/The Lighthouse, a voluntary organization which supports families and children with life-threatening illnesses or disabilities. Isabelle’s presence means that Grace can “start to get a handle on the chaos in my life.” The chaos is not visible to the visitor; the house seems remarkably clean and orderly. But chaos, like respite, is a state of mind.

Respite is “a wading pool,” says Tyler Brann, now 9, of Lunenburg, NS, whose father Raymond has multiple sclerosis. Because MS is exacerbated by heat, the Branns can’t go to the nearby beaches in the summer. But a small caregiver’s grant from the Multiple Sclerosis Society of Canada allowed Tyler to buy a fiberglass pool from Canadian Tire, and bring the beach to his father. (His mother used her grant to buy plants.)

Respite is “small things, like smooth sidewalks for the wheelchair,” says Sharon Hume, who interviewed 30 family caregivers for the Family Caregivers Network Society of Victoria. “That means

more time for the parents together, because they don’t have to deliver their child to school. Or it might mean being encouraged to talk about family caregiving in the company newsletter, and finding the other people in the workplace who are also family caregivers. About 25% to 30% of the working population is involved in family caregiving.”

Respite is picking up dog-droppings in the yard, says Sharla D’Souza of Kirkland, Quebec, whose son Kyle has a wide range of disabilities, from Down’s syndrome to constant small seizures and a tracheotomy for his respiratory problems. “We actually argue about who’s going to clean up the back yard, because it gives a little break to the one who does it.” Respite has many other meanings for the D’Souza’s—a new computer which gives them contact with other caregivers, for example. But the most important are the moments of respite which give them time together as a couple.

Respite is “theatre tickets,” says Carlin MacLeod, a full-time caregiver for his wife Shirley, who has been suffering from MS for 13 of their 37 years of marriage. A small grant from the MS Society allowed him to buy tickets to shows at the grand old Savoy Theatre in Glace Bay, NS. “I made it last from May to December, and I can’t really express in words the lift I got from that little bit of relief. The anticipation kept you on a high, looking forward to the concert, and then the concert would come, and

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that would be wonderful—and I'd enjoy it so much that it would keep me on a high until the next concert."

All the small pleasures of normal family life assume an exaggerated importance when they are not available. Going out for breakfast together, going to a movie, going for a walk, reading, getting one's hair done—things like these become impossible dreams under the relentless, ceaseless pressure of caregiving. For some caregivers, simply getting together with other caregivers, in person or on a listserv, is a welcome relief, putting them in touch with others who truly understand their situation.

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**Respite, in short, is not a fixed cafeteria meal — “today we’re having pork chops” — but a whole buffet of options for the caregiver.**

“The abnormal becomes normal,” Sharla D’Souza remarks. “It’s often a crisis. You get so that you can’t function without that adrenaline rush. I find I feel guilty doing something for myself. And of course you tend to neglect the marital relationship, and that’s so important.”

“There really is no respite in an ultimate sense,” says Donna Scalia, whose daughter suffers from multiple birth disorders. “Like a big newborn baby,” she is speechless and helpless at the age of 12. Ultimately, the caregiver is responsible, Donna notes, and although respite can give temporary relief, the responsibility is always there. But Donna has three other children, and for her, respite means simply being able to go out and have a few hours of normal life with the rest of her family—a restaurant meal, a movie.

The health care system normally considers respite to be the provision of aid which allows the caregiver to get away from his/her responsibilities at least briefly—“replacement care,” so to speak. The patient can be left for a weekend in a lodge or a nursing home, or someone else can come into the home and take care of the patient while the caregiver gets some time off. Unquestionably, replacement care is an important form of respite—but it assumes that respite *for the caregiver* will naturally result from services *to the care recipient*.

This is not a safe assumption. If respite truly is not the service provided, but the caregiver’s experience—the outcome of the service—then no one type of respite can ever meet the whole range of caregiver needs. For some caregivers, volunteering in a caregivers’ support group is itself a welcome respite. Respite may result, not from the

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separation of the caregiver from the recipient which is implied in replacement care, but from enhancements to their shared quality of life—a gift, so to speak, which they can enjoy together. Theatre tickets, a wading pool, and a computer—such gifts reduce the caregiver’s isolation and deprivation, which may be just as draining as the physical burden.

Respite, in short, is not a fixed cafeteria meal—“today we’re having pork chops”—but a whole buffet of options for the caregiver. An impossible dream? Not really. As the Multiple Sclerosis Society project shows, the service provider can set the parameters, and invite caregivers to choose within those limits. Similar publicly funded processes already exist in arts councils across the country, which receive a huge variety of applications, and commission peer juries to select grant recipients.

A vital component of respite is the knowledge that the caregiver’s family member or friend is safe and happy while the caregiver is engaged in respite. Caregivers never cease to care, even when they are physically absent. They will not truly relax and focus on their own well-being if they have even the faintest sense that they may be neglecting their responsibilities.

In the best respite experiences, caregivers know that while they are obtaining respite, the lives of the

ones they care for are being enriched by positive experiences which the caregiver alone cannot provide. While the husband goes for a swim, his disabled wife is having her hair styled. While the parents go out for lunch, their child is learning to paint with watercolours.

Effective respite also provides an intangible benefit by way of recognition for caregivers, which in turn leads to more constructive self-care. Asking caregivers to define their own respite provides “an opportunity for caregivers to reflect on their own needs,” says Michelle Gibbens of the Multiple Sclerosis Society of Canada. Most caregivers tend to be so focused on their role that they ignore their own welfare—but after defining their own respite and experiencing its benefits, they “realize how important that is, and they resolve to pay more attention to their personal well-being in the future.” One caregiver remarked that she hadn’t ever asked for respite because “when you’re overwhelmed, just calling to ask for help is too big a mountain to cross.”

“Everybody always asks, ‘How is Ted doing?’” says one woman. “But when someone says, ‘How are *you* doing?’ I’m always so surprised.”

# *Making Respite Accessible*

THREE APPROACHES

*Given the importance of respite (and the growing role of family caregiving in health care) why is flexible respite so difficult to obtain? What can be done to make it more accessible? The eight projects funded by the Foundation took three broad approaches to the problem.*

## **1. The Power of Information**

One group of projects attacked the issue of caregiver isolation, and lack of information. Many caregivers do not think of themselves as “caregivers;” they’re just people who are caring for family members. And the finest respite program in the world would be worthless if caregivers did not know about it, or could not avail themselves of it. Conversely, caregivers can benefit simply by sharing experiences and information with one another. “The support group is where I cry,” one woman says. “I don’t want to cry at home and upset the family. But at the support group, everybody knows what you’re going through, because they’re going through it too, and it’s all right to cry.”



FAMILY  
CAREGIVERS  
NETWORK  
SOCIETY



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**The Family Caregivers’ Network Society of Victoria** interviewed 30 caregivers, discussed the results with an advisory committee, and then took concrete steps. One issue was the invisibility of caregiving in the workplace; to address that, employees at a local community college and a chain of grocery stores wrote contributions for the employers’ newsletters about family caregiving. That drew together a group of employees involved in caregiving, and resulted in an Internet discussion group at the college. Both the college and the grocery chain head office hosted a series of “brown bag lunches” on caregiving for employees. The Victoria project also developed a resource guide for family caregivers, designed to help caregivers navigate the health-care system and to support them through the complexity of caregiving.



**The Family Caregivers' Association of Nova Scotia** in Halifax used its funding to help

start the first provincial association of caregivers in Canada. The FCgANS' mission is to value, recognize and support family caregivers, defined as those who provide support and care to family and/or friends. More than half of Nova Scotia's caregivers live in rural areas, with few available or flexible supports. "For example, one woman who has been in touch with us can't get respite workers in her home because her son smokes. In another case, the grandparents who are caring for their grandchild can't get any help because they're not the child's custodians—but the custodian is their daughter, who is in hospital with cancer," explains FCgANS' Executive Director, Gail Bruhm.

FCgANS disseminates information by means of a newsletter, a web site and a toll-free support line. As well, with funding from Health Canada the Association is creating work-life balance events for employers and employees who are caregivers. FCgANS was able to leverage the Foundation's support to secure additional funding from the provincial government into 2006.



**The Seniors Resource Centre of Newfoundland and Labrador** in St. John's faced similar challenges of population and distance, and focused their project on connecting caregivers with existing services. As with the Nova Scotia association, the Newfoundland project involved the creation of a newsletter and a toll-free support

line—which was intended to refer caregivers to local services, but often wound up providing counseling itself, when no such services existed in the caller's area.

The project also involved setting up regional networks of caregivers and supporters across the province. The networks themselves have undertaken various initiatives, including directories of services available, support groups, potluck suppers, and "Days Away" for caregivers, which include education, humour, relaxation and mutual support.





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## PROVIDENCE CENTRE

**The Providence Centre** is located in Scarborough, Ontario, one of the most multi-cultural communities in Canada. The Centre's 24-hour Alzheimer's program, for example, serves people who speak 29 languages. The caregiver project's objective, says Amanda Falotico, who oversees it, was to develop a model of support for caregivers in immigrant and ethnic groups who might be isolated by language and culture from mainstream programs. The Centre set up a steering committee focused on the Tamil community. There are 200,000 Tamils in the Toronto area, most of them in Scarborough. But the cultural gap is immense.

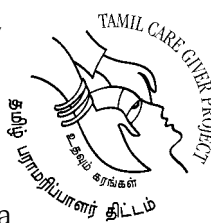
The concept of a "caring for a caregiver" is foreign to Tamil culture, according to Jeyasingh David, the project's manager. Caring for the sick is the responsibility of the most immediate member of the family, and it is performed as a duty. And there are stigmas associated with specific illnesses. So, says Amanda, "a lot of our work involved just trying to figure out what caregiving is, in the Tamil community."

"We are still groping in the dark," agrees Dr. Vannithambi Buvanendran, a member of the steering committee, and the primary caregiver for his disabled wife. "We have still not gotten to the focus,

which is to give respite care, but we can't do it until we identify the caregivers and see what they want."

What Tamil caregivers clearly do want, however, is information about specific medical conditions—especially common ones like diabetes and cancer—and they flock to the Tamil-language seminars that provide it. That's the start. Jeyasingh now has a list of 130 Tamil caregivers, and the project has created a directory of "Tamil-friendly" services and agencies. It has generated a newsletter and a unique web site with information in English and in Tamil for Tamil caregivers, and participates in a Tamil Service Providers' Coalition. It is planning to work with the University of Toronto to develop a Hindu Spiritual Support Worker certification to provide counseling and consolation to hospitalized Tamils with serious illnesses or terminal conditions. Finally, the project is actively investigating the possibility of making suitable provisions for a culturally appropriate long-term care facility for the Tamil community.

The McConnell Foundation funding for the Tamil project officially ended in mid-2003, but the project's obvious value has resulted in additional funding under the auspices of the local Community Care Access Centre.



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## 2. Influencing Health Professionals

A second group of projects turned their attention to health professionals and their relationship to caregivers. With honourable exceptions, health professionals have tended to be very much in command of diagnosis and treatment, focusing their attention on the patient to the exclusion of the caregiver. But when most of the care, day in and day out, is being provided by the family caregiver, such an approach is both alienating and ineffective.



**The Victorian Order of Nurses (VON)** (National Office) calls its project “Learning to Listen — Listening to Learn.” This venerable organization has provided respite services in

the form of replacement care for many years, but it recognized that these services do not invariably yield respite as an outcome. VON’s participation in the project was stimulated by its desire to find better ways of supporting family members, which could be incorporated into VON’s practice. In focus groups with caregivers in five centres across the country, VON asked caregivers what they needed, and how VON staff might better listen to caregivers and respond to them.

Caregivers responded that they wanted flexibility and continuity. They wanted a sense of partnership, a sense that the caregiver and the provider were working together to provide the most appropriate care for the client. They also wanted providers to recognize that their workplace was also the caregiver’s home. Based on this and other research, VON Canada is now developing guidelines and a curriculum for its own staff—a resource which may also be made available to other health-care service providers.





### The Hamilton-Wentworth Caregiver Respite and Support Project (CaReS)

devised a research project to determine the most urgent needs of caregivers in their area, and to obtain their ideas about how to meet those needs. Based on a survey of 299 caregivers, and a shorter survey with 425 service providers—including faith leaders as well as physicians, nurses and service-agency workers—CaReS developed a number of services for caregivers, including one-day workshops, pre-recorded telephone messages with caregiver information, and a Website.

The project ultimately created a “toolkit” for other communities to use in improving their services to caregivers, and especially the provision of respite in a form that would respond to caregiver voices and respect their choices. The toolkit is posted on their Website.

In addition to these two projects, the Victoria **Family Caregivers Network Society** project held team building meetings and workshops in long-term care facilities to enhance relationships among caregivers, residents and facility staff. As well, students training to work as health care providers learned about family caregivers and how to communicate effectively with them. Information on these sessions is contained in a Facilitators Manual developed through the project.

## 3. Direct Interventions with Caregivers

A third group of projects focused on the direct provision of respite to caregivers.



**Le Phare/The Lighthouse** is a Montreal organization dedicated to serving families with seriously ill or disabled children. One of its programs, launched with funding from the McConnell Foundation, has developed individualized recreational activities delivered primarily in the home by carefully screened volunteers. The volunteer, in consultation with the parents, determines the nature of the activity, which can range from bowling to reading aloud, from handicrafts to walking in the park, from playing computer games to drawing and painting. The volunteers visit the families from two to 12 hours weekly, and during the visits the parents are free to do other things. In addition to receiving respite, many parents feel that the volunteers stimulate their children and give them valuable experiences which the parents could not otherwise provide.



The **Multiple Sclerosis Society of Canada** (National Office) developed a very simple, powerful program called a “Caregiver Special Assistance Program,” which awarded grants of up to \$300 for caregivers to spend on virtually any goods or services which they believed would provide them with respite. The requests varied widely—theatre tickets and wading pools, for instance, but also a weekend at a spa, a power washer for the car. Caregivers were particularly pleased that this program respected their right to define respite for themselves—and 95% of recipients reported that they did achieve the respite they had hoped for.

“Initially we used the language of financial assistance,” says the project manager, Michelle Gibbens, “but we soon came to realize that the program was actually using money as a tool to deliver an individualized service. It also created what we’re calling ‘caregiver recognition,’ confirming that caregivers had their own needs, and their work had real value.”

In effect, the grants gave caregivers implicit permission to be kind to themselves.

**The Family Caregivers’ Association of Nova Scotia** provided modest funding to nine community-based respite projects that directly benefited caregivers across the province through such initiatives as support groups, wellness programs, resource baskets and breaks.



# — The Future of Caregiving —

**F**amily caregiving already makes an enormous contribution to health care in Canada, and the evolution of the official health-care system is likely to increase its importance. Taken together, however, these projects clearly show that many family caregivers are already stretched to the limits of their endurance.

There are already something between 2.8 million and 4.5 million family caregivers in Canada, depending on whose figures you choose—“one Canadian in eight, over the age of 15,” says Dr. Karen Szala-Meneok of Hamilton-Wentworth CaReS—and they pay a price for their dedication which can be personally catastrophic. Marriages fail, families are plunged into poverty, and caregivers’ psychological and physical health deteriorates. If public policy is going to ask patients and their families to take even more responsibility for health care, then the care of caregivers will be a matter of profound and growing urgency.

One may be forgiven for speculating that the reason more Canadians are being cared for at home is not only that the home environment may be better than an institution for an ailing person—though it often is—but that policymakers fail to recognize the impact of shifting the burden from the formal system to the families. A patient discharged from the formal system disappears from the accounting system, and vanishes from the

policy horizon. But the cost of providing care has not gone away; it has simply been shifted to the family.

Caregivers remain silent and invisible because they are generally too busy giving care to engage in consciousness-raising or protest. Indeed, caregivers are sometimes resistant even to thinking of themselves as “caregivers.” As one woman put it, “I’m not ‘a caregiver,’ dammit, I’m his *wife!*” But as home-care becomes a more and more common feature of the system, caregivers need to become a more visible interest group, a recognized constituency within the health care system.

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**...as home-care becomes a more and more common feature of the system, caregivers need to become a more visible interest group, a recognized constituency within the health care system.**

Policymakers must learn that the price of shifting more care to the homes may be carnage in the lives of families and individuals—and that price is too high. It may even be too high in financial terms; a

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burned-out, ailing caregiver becomes another patient for the system to support.

In short, there is a sound case for increased home care as an important component of a reformed health-care system. But we should not delude ourselves that it has no costs, or that it will necessarily yield great economies. A humane program of home care which makes life bearable for caregivers over long periods of time will involve a great deal of support for caregivers, perhaps at considerable expense. A positive step in this direction is the new Employment Insurance provision for compassionate care benefits, which, effective January 1, 2004, allows employed caregivers to apply for up to six weeks of paid leave to care for a dying relative.

If a stronger focus on home care means a better quality of life for the chronically and terminally ill, it can be worth pursuing even if there is no saving at all. But we cannot justify doing it on the backs of devoted family members. We must also recognize that not all families can provide the same level of care and that what is possible in a three-month emergency may not be possible as a lifelong commitment.

If we are going to ask more of Canadian families in these demanding situations, then we also have to give them more—more financial aid, more help in

participating in or returning to the workforce, more recognition and respect, more flexibility in our assistance to them, more respite, more support of every kind. These projects point the way to such a future—and underline the urgent need for such sensitive, extensive and individualized support.

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# *The Caregiver's Commitment*

"Caring for my wife for 25 years was very satisfying," says Bill. "But that was because I had the most wonderful patient."

"Every day with my son is a gift," says Sharla. "He has a gift of loving people just as they are. His face, when he smiles, is like the sun."

"We've been married since 38 years, and we were going together seven years before we were married," says Jean. "We've been together since I was 14. And now I have to shower and shave him and all, God love him, but still, I just love him to death."

"Caregiving is great, but it's awful," says Dr. Karen Szala-Meneok. "That's what caregivers told us. It's not simple. It's messy. Sometimes it's wonderful, sometimes it's terrible." Anyone who spends much time with caregivers soon recognizes the truth of these observations. There is plenty of bitterness, resentment, depression and anger in caregivers, and all the neurotic or even pathological features of family life are carried over into the lives of various caregivers.

But in the end, one is also left with a sense of wonder at the strength, tenderness and endurance which so many apparently ordinary people can summon up when a loved one is in deep distress. Adversity strips trivialities away, burns relationships down to their core—and what emerges from that trial by fire is a strength of character, a capacity for love, which are as beautiful as rich, rare blossoms.

Carlin MacLeod, who bought theatre tickets with his caregiver grant, sits in his modest bungalow in the former coal-mining town of New Waterford, Nova Scotia, and reflects on the quality of his life.

"Shirley got sick in 1992, and I've looked after her from Day One," he says. "I get up at 7:00 and I do all the housework, the cooking and cleaning and what-not. At noon I get my grandson from school, and after dinner I get him back there.

"I have to get Shirley up and ready for the day, get her medication, get her dressed and everything. And I stay up until she goes to bed, because I got to put her there. In the evenings we read, or watch TV, or just sit and talk together. She's so special to me. We've been married 37 years, and I just fill up and have to stop talking when I think about all this....

"Sometimes I dream about her walking again. If she walked two steps, I'd be the happiest person in this world. And sometimes it's hard caring for her, like trying to do her hair and it's coming out in handfuls, and it's just breaking my heart. I'm trying so hard to be careful, trying to be so gentle—and still it's coming out in handfuls...

"But this is what you promise when you get married, isn't it? Looking after Shirley is nothing I'd ever give up."

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# About the Author

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photo: Don Robinson

Silver Donald Cameron is one of Canada's most versatile and widely-published authors. His 15 books include novels, social and literary criticism, travel and nature writing and humour. His essays and articles have earned four National Magazine Awards, and he has won numerous other awards for his work in radio, television and the stage. He was formerly a columnist with *The Globe and Mail*, and currently writes a weekly column for the *Halifax Sunday Herald*. Dr. Cameron has taught at four universities, and been writer-in-residence at three more. He was the first Dean of the School of Community Studies at the University College of Cape Berton. As a citizen, businessman and consultant, he has been intensely involved with community economic development in Isle Madame, Nova Scotia, where he has lived since 1971. He is also a popular speaker who uses humour and storytelling to enliven his provocative thoughts on a variety of issues.