

In an aging society, pity the caregivers

The Ottawa Citizen Tuesday, February 12, 2008 Page: A12 Section: News

Byline: Elizabeth Payne

Column: Elizabeth Payne Source: The Ottawa Citizen

It is performed mainly by women at all hours of day and night on little sleep for no pay. It is so undervalued that few even recognize it as a sector of the economy. Yet, if all the voluntary eldercare workers in Canada stopped changing diapers, holding shaking hands, buying groceries, fetching medicines and sitting up nights by the bedsides of elderly relatives and friends, it would cost the health care system an estimated \$5 billion a year to replace them -- if it could even begin to. And that may be the real point. While plenty of attention has been paid to child care, the public debate about the plight of eldercare workers is almost non-existent. Citizen reporter Pauline Tam, in her series "The Age of Methuselah: Canada's Longevity Boom," offered glimpses into the heroic and exhausting lives of caregivers such as Donna Ivany, who dedicated her life to caring for others to help fill a void after the deaths of her own parents, and Judy Cutler, who struggled to find her way back into the workforce after caring for her mother and brother, both of whom died of cancer.

Most often, the caregivers who help Canadians through serious illnesses or their final days are female family members. Women have done the bulk of caregiving for decades, centuries even, but times have changed. Now, record numbers of women are in the paid workforce. That, combined with the coming boom in the elderly, has created a serious care gap and a real need for a national strategy on caregiving. The looming crisis in eldercare is being hurried along by the lack of well organized support for those who provide care out of a sense of love and duty and would have it no other way. To many, it must seem that the system conspires to make this as difficult as possible. The trouble is, voluntary eldercare workers tend to be invisible, impoverished and exhausted -- not the makings of a strong lobby group. Some simply struggle to keep themselves mentally, physically and financially solvent after long months or years of intensive caregiving. When doctors diagnose patients with Alzheimer's disease, they routinely warn their family members that their health is also at risk. "This disease often takes two victims," my mother-in-law was told. "Don't let that happen to you." The toll on caregivers is widely acknowledged, but help can still be difficult to come by.

Still, there are some encouraging signs of progress. Last year, a respite care bungalow was opened at the Perley and Rideau Veteran's Health Care Centre in Ottawa with 12 rooms for

Alzheimer and dementia patients whose caregivers are in need of a break. The guest house, jointly funded by the Alzheimer Society of Ottawa, the Victorian Order of Nurses Ottawa-Renfrew County Branch, the Perley and Rideau Veterans' centre and donations, was built in response to a report identifying an urgent need for respite care in the community. But across the country, help remains spotty and those who need it are not always identified until they can no longer cope. Judy Cutler, who now works for CARP, Canada's Association for the Fifty-plus, said she had no respite help when caring for her dying mother in Montreal and was later offered one weekend a month while she cared for her brother who was both schizophrenic and suffering from cancer. Respite care, she said, is a "hit and miss thing ... almost like a luxury. It really is part of the package for the caregiver before burnout. It is not a frill."

Groups including the Alzheimer Society would like to see a national caregivers' strategy which would include a better organized, better funded system of respite care, starting with a review of what is there now and what is needed. There are also calls for more financial support for caregivers. Currently, six weeks of Employment Insurance funding is available for those caring for dying relatives, but many caregivers don't qualify because they have been out of the workforce for too long. Judy Cutler argues that eldercare workers should receive financial support similar to that given to new parents. Others, including Liberal Senator Sharon Carstairs, say the Canada Pension Plan should be made more fair to caregivers. And fairness is the bottom line. Caregivers are in real danger of mass burnout. They deserve the attention that they don't have the time and energy to seek for themselves. Five billion dollars is a lot of money. But it comes nowhere near measuring the real value of what eldercare workers are doing.

Elizabeth Payne is a member of the Citizen's editorial board.