

Folio: Dementia

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Isolated by affliction, isolated by language

Those stricken with dementia face a world in which the once familiar is strange, once-friendly faces are unrecognizable, once-treasured memories no longer exist; a world of growing darkness. And those who learned one of Canada's two official languages later in life face an even more vexing problem: Imagine suffering from this disorder after your ability to comprehend English or French falls away, existing in an environment where everything is foreign, including the words – you understand no one, and no one understands you. It's a growing problem in Canada, where dementia is on the rise and a large portion of an aging populace has a minority mother tongue, and it means a radical shift in care is required, **Erin Anderssen** writes



TOP: Caribque Tse's mother, Connie Chan, lives at the Chinese-language Yee Hong Centre in Markham, Ont.

ABOVE: Ms. Chan, having her hair done by her daughter, suffers from Alzheimer's disease and first spent time at an English-only facility – 'Nobody could chat with her' – before moving to the Yee Hong Centre.

LEFT: Despite the progression of her disease, Ms. Chan 'is so much happier' at the Yee Hong Centre, Ms. Tse says.

AT TOP: Picture cards are used in some facilities in British Columbia to work around language barriers.

PHOTOS BY PETER POWER/THE GLOBE AND MAIL

Mary-Ann Billington is never sure which language her mother will use – as if the 85-year-old's brain, stricken with Alzheimer's disease, has jumbled her words. Ask her a question in Dutch, the language of her childhood, and she might answer in English, which she learned fluently as an adult. She mashes Dutch and English into one sentence, or makes up words altogether. She gets frustrated when she isn't understood. "We would just nod and smile if we didn't understand what she was saying," said Ms. Billington, a researcher with Statistics Canada in London, Ont.

Dementia is already an isolating disorder. But it becomes even more complicated because patients, with their memories collapsing back to childhood, often lose their ability to speak English if they learned the language later in life. In a nation where the incidence of dementia is expected to double in the next 30 years to one million people – and in which 20 per cent of an aging population has a mother tongue other than English or French – that means a huge strain on families looking for good care, and will require a radical shift in the country's health-care services. Language barriers for dementia patients "are not taken very seriously at all levels of society," said Jeff Small, a linguistics professor at the University of British Columbia. "Do we just feed people, toilet them, make sure they have

clean clothes? Is that the extent we owe them as a society?" Even in major cities such as Toronto and Vancouver, beds in nursing homes in which staff speak minority languages are in short supply, and families looking for home-care support are often expected to take whatever is available. Of the more than 600 long-term-care homes in Ontario, about 80 have some form of culturally specific programming. Some may offer ethnic food, while others have floors designed for people of a specific ethnicity, and a few provide services exclusively for one culture. There are signs of progress: government health agencies are working to hire staff who speak a variety of languages, and funding in some provinces has supported facilities such as the Rose of Sharon residence, which opened last year in Toronto to

serve Korean seniors. But astonishing gaps remain: Of the 17 homes with beds for ethnic groups, none serve the city's growing South Asian community. Francophones in the GTA – who number about 80,000 – have access to only 37 spaces guaranteed to have French-speaking staff. Across the country, in smaller cities, the situation is far worse for minority groups. But even Surrey, B.C., a region with a substantial South Asian population, has only one assisted-living seniors' residence for that demographic – and its 72 spaces are not designed for patients suffering from dementia. "People are dumped into regular-care homes where staff are not bilingual, and their lives are cut short," said Charan Gill, chief executive officer of the Progressive Intercultural Community

Services Society, which partnered with the provincial government to build the existing residence and has been campaigning for a dementia-specific facility. A lack of care options, Mr. Gill suggests, means that families are keeping elderly parents home longer than may be safe, sometimes leaving them alone when they need supervision. Some agitated patients in care facilities may have to be placed in restraints because language barriers prevent staff from understanding the reasons for their distress, according to Serena Tin, a social worker at the Yee Hong Centre, a nursing home for Chinese seniors in the Toronto area. "What happens when they are scared?" she said. "What happens when they have a bad dream? Who is going to help them? They need someone to comfort them."

In a new study led by Dr. Small, researchers studying on-camera staff and patient interactions at two long-term-care facilities in British Columbia discovered that when caregivers didn't speak the same language as the patients, interactions declined dramatically – and attempts to speak in the same language, with single words or phrases, were largely limited to practical subjects such as bathing, rather than social conversations. In some cases, said Dr. Small, cultural differences – such as the meaning of a nod – caused confusion. For families, a lack of suitable care results in untenable situations. In Surrey, for instance, Devinder Shattha and her family refused to place her mother in an English-only home, and juggle work schedules to watch her constantly – she forgets to eat,

and often wanders at night. "She would be totally lost," Ms. Shattha said. "I look into her eyes and see confusion. She is already confused when we speak Punjabi."

Toronto accountant Sylvie Lavoie chose a facility in Welland, two hours away, when her mother had to be placed in care after a fall, because the staff spoke French. Her mother, who spoke English fluently for most of her life, lost the ability as her dementia progressed. Ms. Lavoie worried her mom would be in pain and no one would come to her aid. "It's absolutely cruel to stick someone in a place where no one can understand you."

So far, many of the facilities that serve ethnic groups in Canada grew out of grassroots communities, with governments contributing financially, or as private homes recognized a need

in their area. Beyond beds, this is also an issue of human resources, and more doctors and nurses are being recruited from immigrant communities. To bridge the gap in the meantime, some hospitals, including Mount Saint Joseph in Vancouver, are using recordings in various languages to provide information, or picture cards that patients or staff can flash at each other to interpret different requests and needs. But the health-care system is still trying to catch up to a shift in immigration, said Stacey Daub, CEO of the Toronto Central Community Care Access Centre, which co-ordinates home care and residential wait lists. Canadians will also have to be realistic about where they live, she said, in the same way they may choose an age-friendly house when they retire. "If you

know you are going to need certain type of services, you need to start planning for that." Right now, it's more often a question of luck – as in the case of Connie Chan, whose daughter, Caribque Tse, had to initially place her in an English-only facility when her Alzheimer's made her care at home impossible. The staff tried to communicate using hand gestures, Ms. Tse said, and assisted her mom with games of bingo. "Nobody could chat with her," she recalled. "She only smiled at them, said 'Good Morning,' and 'Hello,' that was it." Then a room became available at Yee Hong, where, until her condition worsened, Ms. Chan was able to spend her days, reassured by the familiar, playing lively games of Mahjong. Even now, confined to a wheelchair, Ms. Tse said, "she is so much happier."

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Sylvie Lavoie
After dementia stole her mother's ability to speak English, the Torontonian placed her in a care facility in which the staff spoke French, a language she could still understand