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## The toughest choice

Dealing with an aging parent isn't just emotionally difficult: it also involves a confusing array of services, from in-home care to nursing homes.

By <u>David Aston</u> | From MoneySense Magazine, <u>April/May 2012</u>



Back in 2008, Lise Hafner and her two brothers sensed something was not quite right with their mom. Then the doctor made the dreaded diagnosis: Priscilla Hafner, their energetic and independent 78-year-old mother who lived alone in Toronto, was in the early stages of Alzheimer's disease.

Lise and her brothers realized their mother was facing a hard road. How could they ensure their mother was safe? How could they honour their mother's wish to remain in her home "until she was carried out feet first?" And how much would it all cost?

Chances are you or a loved one will one day be in a situation much like the Hafners, where you're making arrangements for an aging parent who needs help with daily activities. And like Priscilla, most people probably prefer to get that care in their own home, at least while it remains a viable choice.

Unfortunately, just understanding the patchwork system of private and public senior care is no small feat.

To help, we'll describe what you can expect from in-home care. Then we'll advise what help governments typically provide, and what you'll need to pay for yourself. We'll help you understand when in-home care makes the most sense, and describe when a retirement residence or a nursing home are better alternatives. You may be surprised to learn these options are more attractive than you think.

Get by with a little help. When a parent or other relative starts to get frail, daily tasks often start to slip. Perhaps housework and yard work start to build up, and it is hard to keep fresh food in the fridge. The parent may no longer drive, and may have trouble managing basic activities like bathing, changing, preparing meals, or keeping track of their medications. The children often get more involved at this stage, but they are probably busy with their own families and jobs, and may not even live close by. It's easy to feel overwhelmed.

"Get help before you're totally exhausted," suggests Peter Silin, a care manager and principal with Diamond Geriatrics, Inc. of Vancouver. (Care managers are typically hired by families to oversee care for a loved one.) There's a whole industry of in-home caregivers devoted to helping frail seniors with daily activities. While you may feel guilty about off-loading these tasks, you'll find that it frees you up to spend more meaningful time with your parent.

When you think of in-home care, you might picture it being done by a nurse. But most paid care in the home is provided by legions of hardworking paraprofessionals with job titles like "personal support worker" or "personal care worker." They don't have medical training, but they know all about helping with mundane activities like bathing, changing clothes, toileting, grooming, getting groceries, preparing meals, helping frail seniors eat, doing housework, driving to appointments, and helping your loved one get around the house. You can hire these personal care workers yourself, go through an agency, or sometimes get these services assigned and supported by governments. Providers range from non-profits like the Victorian Order of Nurses, to small local businesses, to large national companies.

If your loved one is mobile and needs just a bit of help, a personal care worker might come twice a week for two hours each to help with bathing and grooming. If your parent needs more help, the worker might come once a day to help with changing, toileting and preparing a hot meal as well.

Other home care needs may arise on a shorter-term basis, such as after an operation. (And here nurses are more likely to directly provide care.) Or if an elderly person is near the end of life, the hospital may send him or her home to be with family but have a nurse stop by periodically to provide pain medication. That's what's known as "palliative" care.

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When Diane Speirs's aunt came home from the hospital in Vancouver after falling and breaking her arm, a personal care worker visited for up to 1½ hours every day to help her change clothes and sanitary garments, clean the bathroom and kitchen, help her bathe and do laundry. But Diane and her husband Brian also visited four or five times a week to bring groceries, help with housework and yard work, pay bills and take her to doctor's appointments. "We did whatever else needed to be done," says Diane.

Who picks up the bill? At this point you're probably wondering who pays for all this care. The good news is provincial governments will help out—but only so much. Short-term post-operative or palliative care are frequently covered, but beyond that, governments keep a tight hand on their wallets.

Typically provincial governments provide in-home care through a regional health agency. (They're called local "health authorities" in B.C. and "community care access centres" in Ontario.) If you're looking for government help, you can get a referral from the family doctor or contact your local health agency directly. On request, they'll generally send a case manager to assess your loved one's needs. They allocate their support based on need, and in some provinces, also on your ability to afford care yourself. The maximum you can generally expect government to pay for is two hours a day, says John Schram, president of the Canadian Home Care Association. Unfortunately, "that quite often isn't enough. There's a huge gap between what people need and what they typically get," says Schram, who is also CEO of We Care Home Health Services LP.

Nothing is automatic, even for basic forms of government-paid help: you need to make your case persuasively. For example, in Ontario, "the government realizes that if the risk of falls can be minimized, there's a better chance of keeping that senior safe and in the home," says Audrey Miller, care manager and managing director of Elder Caring Inc. in Toronto. "What I've learned in my time is the way to get some help with bathing is to say something like 'My mother had a fall. I'm concerned she's at risk while bathing because she lives alone."

For what government or family members aren't able to provide, you'll need to pay for yourself—and the costs quickly escalate. Personal care workers hired through an agency typically cost \$20 to \$28 per hour, often with a minimum of two hours or more per visit. A full-time, live-in personal care worker can cost \$1,800 to \$3,000 a month, plus room and board. (Add another \$1,500 to \$2,000 a month if room and board is not provided.) If you need round-the-clock care, that may require two or three full-time caregivers. (Even live-in caregivers can only be asked to work one shift a day, and they require time off.) While most middle-class seniors can afford to pay for a little bit of help, you can quickly get to the point where only the very rich can afford it. "If money is not an issue, you can always make in-home care work, but it might mean making your home into a hospital," says Miller.

**Better than you think.** Eventually you're likely to go beyond the point when in-home care makes sense. Just where that point lies is different for everyone. It depends on your loved ones specific needs, personal preferences, finances, and the practical difficulties of providing extensive care in a family home. Fortunately, the other options are probably better than you think—and they are often within financial reach for middle-class Canadians.

A retirement home may be a good choice for seniors who want their own apartments but also want common meals, housekeeping and social activities in a home-like setting. They often have "independent living" sections for mobile residents who require little or no personal care, as well as "assisted living" for those who need moderate help with bathing, changing, or taking medicine. While retirement homes are not cheap, middle-class Canadians can usually afford them with the proceeds from selling their home.

If your loved one needs a lot of care—say he or she has advanced dementia or requires help with the most basic activities like transferring from a bed to a chair or toilet—it may be time for a publicly supported and regulated nursing home. We know what you're thinking. The idea evokes images of dreary Victorian-era wards, but nursing homes these days are much homier and less institutional than you may think. (Confusingly, nursing homes go by many other names these days, such as "long-term care" in Ontario and "residential care" in B.C. )

Even if you can afford the most elaborate and expensive in-home care possible, your parent may prefer the social interaction of a retirement residence or nursing home to isolation. "You can buy all the services you need at home, but you can't buy a community, a peer group, which you can get in assisted living, independent living or a nursing home," says care manager Silin, who is also author of *Nursing Homes and Assisted Living*.

**The Hafners' journey.** The right care option for your parent or loved one is ultimately a personal decision. Consider the journey the Hafners went through after Priscilla was diagnosed with Alzheimer's. Lise and her brothers, Eric and Gordon, realized

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they needed help to keep her as safe and happy as possible.

The three siblings lived many miles away with families of their own in separate U.S. cities. As a result, they were limited in how much time they could spend directly caring for their mom in Toronto. Priscilla was an energetic, no-nonsense woman who had lived on her own since her husband died in 1994. But the combination of an independent spirit and the symptoms of the disease made their mother difficult to help. She turned down pleas from her children to move closer to one of them. That's not surprising: seniors with Alzheimer's tend to cherish familiar surroundings and get along best with people they know.

Lise and her brothers started off hiring a driver to take their mother to her daily appointments and other outings. That was enough for a while, but as the disease progressed they found Priscilla needed more. The next step was finding a live-in caregiver and making a few changes to the townhouse, like removing the knobs from the gas stove. Eventually they needed three live-in caregivers providing round-the-clock support. The siblings realized they were unable to coordinate all of this from afar. "Don't underestimate the logistics," Lise advises. "It's expensive. It's exhausting. It's emotionally draining."

The Hafners hired Audrey Miller of Elder Caring Inc. as care manager to handle the staff, monitor their mom's condition, and take her to doctor's appointments.

Gradually the elaborate system of in-home care became unworkable. As Priscilla's Alzheimer's got worse and other medical issues developed, they realized her home was no longer safe. And although they felt conflicted, they realized the need for safety trumped their desire to fulfill their mother's wishes to stay in her home. "The time came when we just could not keep her in her home any longer," Lise says.

So recently the three kids moved Priscilla to a facility that provides long-term specialized care for seniors with dementia. Now they're working to make life as rich as possible in this new setting. "Is it ideal?" Lise asks. "No. But I think we all have a sense of relief, because we know we're over the first major hurdle, because she is safe."

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