

## With Dignity and Respect

### Helping families understand dementia and its expected progression

*This short fictional narrative tells the story of a person experiencing the typical course of Alzheimer's dementia and highlights the impact on the person, but also the person's family.*

Lois Miller was an elementary school teacher and principal—a job that defined her. She was intelligent, funny, committed, and popular with both students and other teachers. After Lois retired, she became even more involved in the community. To help children who were behind in their reading skills, she developed a reading program at the local library and helped out with the hot breakfast program in several local schools.

Lois and her husband Martin raised a daughter, Lindsay, who was now married and also a teacher. Looking back, Lois thought that her life had been nearly perfect, with many accomplishments, a successful, meaningful career, and an enjoyable family life.

At 85, Lois was diagnosed with congestive heart failure, although managed quite well with medications. She occasionally felt short of breath while climbing stairs, but her heart problems never seriously interfered with her ability to participate in her volunteer activities.

Around Lois' 86<sup>th</sup> birthday, Martin noticed that his wife's legs had swelled and that she became short of breath after dressing. Lois' doctors figured out that these symptoms developed because Lois was forgetting to take her medications. The situation quickly improved after Lois took her medications regularly, thanks to daily reminders from Martin.

At first, no one was overly concerned about Lois' small lapses in memory, such as forgetting to take medications. After all, everyone forgets to take their medications now and then. But when Martin had to remind Lois of their first grandchild's name, he began to worry. It wasn't long before Martin noticed that Lois was having more difficulty doing



things around the house, such as baking bread, something that Lois had done every Saturday since she and Martin married. Martin realized that his wife was forgetting to pay bills and couldn't always remember how to play cribbage. Lois' memory was steadily getting worse, as was her ability to carry out everyday tasks.

Martin took his wife to the doctor, who diagnosed Alzheimer's dementia. Upon hearing the diagnosis, Martin realized that he didn't know much about the condition. He didn't know how to help Lois manage her dementia, nor how to cope with it himself.

Lois was referred to the PATH Clinic for education and help with decision-making and planning. PATH stands for Palliative and Therapeutic Harmonization. PATH evaluates a person's overall health (including physical, cognitive and social health) and helps patients and their families learn how to approach important medical decisions. Greater understanding helps people make well-informed decisions to ensure a comfortable life and, eventually, a dignified death.

## Understanding dementia

Dementia can be caused by many diseases, including vascular disease (strokes in the brain) and, more commonly, Alzheimer's disease. But no matter the cause, dementia always gets worse over time. It cannot be halted and it cannot be reversed. It shortens an individual's lifespan and is always fatal. Many individuals with dementia have other illnesses, which also shorten life. Thus, the course of dementia and the impact of other diseases on a person's health should be fully understood before deciding how to proceed with medical treatments. That's because dementia impacts all aspects of the person's health, particularly their ability to withstand medical procedures. That knowledge is crucial in making good decisions about medical care. It will also help prepare patients and families for what is to come.

The course of dementia is described in terms of stages – mild, moderate, severe, and very severe. Although every person is different, research shows that each stage generally lasts from 1 ½ to 2 years. Some people decline more quickly, while others may progress at a slower rate. Health professionals use the Brief Cognitive Rating Scale (BCRS) to assess how well people are functioning and thinking and to determine what stage they're in. By understanding the features of each stage, families and caregivers are better able to map the course of the illness.

### Mild stage

In the early or mild stage, people typically have trouble with activities such as shopping, cooking, handling finances, and remembering appointments. To compensate, Lois started keeping lists and notes in a little notebook she carried with her. Her husband stuck Post-It note reminders on the fridge, kitchen cupboards, and mirrors. Despite these, Lois still forgot appointments. Although she regularly watched the evening news, she couldn't remember the details of what was happening in the world. Unable to remember the rules of cribbage, Lois became frustrated at not being able to play well. Lois had a fender bender the year before and although no one was with her at the time, it would not have surprised anyone in the family to learn that Lois had been at fault. After discussion with her family, Lois agreed to stop driving.

Because Lois had more difficulty following



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conversations, she became anxious and reluctant to see friends and attend parties.

Even at this early stage of the disease, relationships begin to suffer. Martin was spending a lot of time supporting Lois and prompting her when she forgot something. It became Martin's role to comfort and soothe his wife. Their marriage, once a loving bond between equals, started to slip into new and unknown territory. Both Martin and Lois needed more support. That's when Martin and their daughter, Lindsay, had a frank conversation about Alzheimer's disease and its effect on Lois. The conversation had them both in tears but brought them closer together. They set to work to establish who could help with what.

### Moderate stage

A little over a year after Martin's conversation with his daughter, Lois progressed to the moderate stage. She paradoxically seemed at times withdrawn and at times restless. Like many people in this stage, Lois had difficulty sleeping. She roamed the house in the middle of the night. She would pick up a book, thinking it would help, but she had trouble remembering the characters and how the plot was unfolding. Watching television was a little better, at least when Lois could figure out how to get the new remote control to work. On one occasion, it became such a frustrating experience that Lois threw the remote at the wall.

Lois' memory problems were becoming more and more obvious. She was able to walk the two blocks to the grocery store, but once there, became confused about what to buy. Neighbors would see Lois on the sidewalk, looking puzzled and glancing up and down the street, slightly short of breath. Thankfully, since most people knew Lois and Martin, they were able to help her home. Lois never got lost, but her family started to worry that she might.

Lois's cognitive problems were casting shadows into almost every corner of life. Dressing herself appropriately was an issue: she wanted to wear the same outfit every day. Martin had to sneak Lois' clothes into the wash at night. Lois started misplacing things and would search for them for hours. She sometimes accused others of taking her things.



Lois continued to tell stories of her youth, but as the family listened to familiar tales, they noticed that details started to drop out. It was as if the story of Lois's life was dissolving.

### Severe stage

In the severe stage, people's behavior may become odd or unusual. Lois became convinced that she and Martin had sold their house and she started piling their belongings near the front door. She wandered from room to room with random objects in her hands, fretting. When Martin gently told her that they weren't moving, Lois didn't recognize him. She thought he was the electrician and told him to get out of her house or she would call the police. Martin knew better than to argue with his wife. He sat outside on their front porch and wept. When he came back inside 10 minutes later, Lois greeted him as if nothing had happened.

At this point in the illness, people with dementia will have severely impaired short-term and long-term memory. Family members and friends may become strangers. Even old memories begin to disintegrate. People may not be able to express themselves or understand what others are saying. People who have been even-tempered and calm all their lives may become agitated, even aggressive at times. In this stage, people need constant supervision if they are to safely stay at home.

Lois found it very difficult to sleep and no medication seemed to make a difference. Often, when they were getting ready for bed, Lois would become anxious and ask Martin if he was going home. Sometimes he would show her a picture of their wedding day to remind her of their marriage, but he still spent many nights in the guest bedroom.

Martin had become Lois' primary caregiver. He bathed her and helped her dress. He grieved for the loss of his wife as he previously knew her and the relationship they once shared. Although the family arranged for a few hours of home care every day to help Martin, having a stranger in the house often upset Lois. Other family members helped when they could, but most of the responsibility fell on Martin. He had always been devoted to Lois and would do everything he could to make her life comfortable, but he feared that it was becoming too much for him to deal with on his own; what if he became ill or the hip surgery he had been waiting for finally got scheduled?

Despite having been physically active and strong all her life, Martin saw that Lois was starting to have difficulty walking. She seemed so uncoordinated that Martin was afraid she would fall and break a hip. She was also having trouble speaking and finding the right words to use. In addition, symptoms of heart failure were worsening. Lois spent more time sitting down and was frequently short of breath after walking even short distances.

Dementia is often a slow process, but the decline is inexorable. Anyone with this illness will continue to deteriorate mentally and physically.

Individuals with dementia are vulnerable. That means it's vital that family members and caregivers carefully consider dementia and its stages, as well as any other illness, when making decisions about medical care. Going to a hospital for any medical procedure is likely to be very confusing for people with dementia. Confusion may lead to further deterioration in functioning and memory that does not always reverse.

Having dementia places people at risk for hospital-related complications, especially delirium. The extreme confusion, aggression, and sharp changes in mood associated with delirium can persist and impair the ability to participate in rehabilitation, making for a longer hospital stay. Paradoxically, many people with dementia are in a worse state when they leave the hospital than when they arrived. Therefore, families and caregivers should clearly and thoroughly understand the potential benefit and risks of any medical intervention.

When Lois was in the severe stage of dementia, her heart problems worsened. Her cardiologist suggested a surgical procedure. Although the specialist said that surgery was needed, neither the family physician nor the specialist doctor seemed to consider the surgical risks *for Lois' brain*. None of Lois' doctors talked about the impact of dementia or the effect the surgery could have on Lois's memory or ability to walk. Instead, everyone spoke as if surgery was required and the decision for surgery had already been made.

However, having been to the PATH clinic, Lois' family was better able to consider Lois' vulnerable health and the potential outcomes from surgery. Realizing that an operation would do Lois more harm than good, her family declined the offer. Lois's welfare and comfort was the family's primary concern, and they would do everything they could to ensure that she had the best quality of life possible and that she could die gracefully, as Martin knew she would have wanted.

## Very severe

Martin knew he could no longer take care of Lois at home. Lois could no longer walk on her own, used only a few words, and needed 24-hour constant care. No matter how much he wished things were different, he just couldn't provide that kind of care. He visited several nursing homes and finally chose one that was close to home. Several months later, and five years after being diagnosed with dementia, Lois moved into the nursing home. Although this transition was extremely difficult for both Lois and her husband, she eventually settled.

A week later, when Martin and their daughter Lindsay came to visit, Lois was nicely dressed, wearing a blue sweater, a pearl necklace, and corduroy pants. Lois could not walk or talk. She sat in her wheelchair, head tilted to one side and her mouth opened wide, her tongue slowly working in and out of her mouth, moaning softly as if chanting. Lindsay pictured what her mother had looked like before dementia destroyed her brain. But now it was hard to recognize her mother. At dinner time, Lindsay watched the staff gently spoon mashed potatoes into her mouth, cleaning food off her chin when her tongue pushed it back out. She turned away before anyone could see the tears well up in her eyes.

Over the next four months, Lois' health continued to decline. She was no longer able to move about in bed and required a mechanical lift to get into a chair. She was losing weight and her breathing worsened so that now Lois was short of breath even with the smallest physical effort, such as when the staff moved her from the bed to the chair. Lois lost control of her bladder and bowels and became irritated when the nursing home staff tried to change her incontinence pads.

One day, Lois' breathing suddenly worsened. She struggled to catch her breath and appeared less alert than usual. The nursing home called the family to ask about hospital transfer. Having been educated, Martin and Lindsay knew that death was imminent and opted for a dignified end of life. They gathered at the nursing home to be with Lois and support each other. As Martin sat by Lois' bed, holding her hand and talking softly, he marveled at how much weight his wife had lost over the past months: she looked like a skeleton. The nursing staff gave Lois medication for pain, but eventually her breathing became labored and her eyes closed. Martin sat there for a long time, comforted by his family and crying quietly, the pain of the past years welling out of him.

Death can be very, very difficult for people with dementia. Many people with this illness die in pain, short of breath and severely agitated. Being unable to speak for themselves, it's up to family and caregivers to ensure that symptoms, especially pain, are well controlled at the very end. PATH is about helping people make good choices about end-of-life care. Death is inevitable, but pain and suffering need not be.

*\* Lois and her family are a composite drawn from many people's experience of dementia.*

## About the PATH Clinic

The PATH clinic is an innovative healthcare service for older people in Nova Scotia with chronic health conditions. PATH provides assessment and consultation to help these people and their families understand their true health status and outlook for the future. The aim is to help people make healthcare decisions that support overall health and quality of life.

Visit us at [www.pathclinic.ca](http://www.pathclinic.ca)

