

# A patient's experience in dementia care

Using the "lived experience" to improve care

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### Abstract

**Objective** To give FPs an understanding of the "lived experience" of dementia via the words of a person with dementia (PWD)—Faye Forbes, a 64-year-old Anglican priest with Alzheimer disease who provides her perspectives on living with dementia—and to use these thoughts to improve care and outcomes.

**Sources of information** Ovid MEDLINE was searched from January 2005 to February 2015 using subject headings for *dementia, caregiver, perspectives, and quality of health care*. Articles geared toward FPs were selected. Relevant review articles and original research articles were used when appropriate and if they were applicable to PWDs and their caregivers.

**Main message** There are several frameworks that organize the main experiences described by patients and caregivers. We used a review of the qualitative literature to provide the framework to summarize Faye's experience under the following headings: seeking a diagnosis, accessing supports and services, information needs, disease management, and communication and attitudes.

**Conclusion** Physicians should consider these themes when developing a management plan for PWDs. Trying to understand the experiences and perspectives of PWDs and their caregivers is important in providing optimal care.

Faye Forbes is a 64-year-old Anglican priest who lives in Halifax, NS. She has been a strong advocate for persons with dementia (PWDs) since she was diagnosed with Alzheimer disease in 2009. This article summarizes her experiences—the experiences of a real person, rather than the details of a composite or fictitious case. It summarizes her experience with dementia in her own words and a medical interpretation of the details of her story is not provided.

*I presented to my FP at age 56 with fatigue, lack of interest, and forgetfulness. As I had been going through some substantial changes in my life, my FP thought it might be mild depression and prescribed medications. Although I was able to continue working, the symptoms worsened. The symptoms also included decreased concentration, insomnia, apathy, communication difficulties, anxiety, and problems with tasks such as laundry, cooking, and paying the bills. Despite treatment, I had to take leave from my job.*

Family physicians play a crucial role in the diagnosis and management of dementia.<sup>1</sup> As the prevalence of dementia increases, this role is becoming even more important. The early

### EDITOR'S KEY POINTS

- Family physicians play a crucial role in the diagnosis and management of dementia. There are challenges to optimal care, including knowledge gaps and uncertainty on the part of physicians, lack of time or remuneration for providing education and counseling, and difficulty identifying resources in the community.
- Patients and caregivers report delays in diagnosis and frustrations with delays in accessing resources and supports, and they identify important management issues in the realm of diagnosis and disclosure, supports and community resources, information sharing, disease management, and attitudes and communication skills. They note that they often feel the need to initiate discussions about management issues such as safety, driving, and medications.
- To provide the best care, physicians must consider management in the context of these themes and try to understand the experience and perspectives of persons with dementia and their caregivers. It might be necessary to refer to or collaborate with other professionals to organize supports and services. Patient and family perceptions are crucial for FPs in gauging symptom response to treatment. Small functional gains, such as being more independent in dressing, can improve the patient's self-esteem and ease burden for caregivers.



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and accurate diagnosis of dementia, and the disclosure and discussion of prognosis and management, are crucial and can have substantial long-term effects for patients and their families.<sup>2</sup> Ongoing support and interventions can improve quality of life and delay the need to move to long-term care. Referral to resources such as the Alzheimer Society and day programs or respite care can also improve outcomes and quality of life.<sup>3,4</sup> Examples of strategies and resources were summarized in an article in the Care of the Elderly series in *Canadian Family Physician*.<sup>4</sup>

There are many challenges to optimal dementia care. These include knowledge gaps and uncertainty on the part of physicians, lack of time or remuneration for providing education and counseling, and challenges identifying resources in the community.<sup>5-7</sup> Patients and families report delays in recognizing and diagnosing cognitive disorders and frustrations with referrals for resources and supports. There is increased interest in the perspectives and experiences of patients and families related to the diagnosis and management of dementia.<sup>8,9</sup> We hope to give FPs a better understanding of the "lived experience" via the words of a PWD, and use these thoughts to improve care and outcomes.

### Sources of information

Ovid MEDLINE was searched from January 2005 to February 2015 using subject headings for *dementia, caregiver, perspectives, and quality of health care*. Articles specific to family practice or FPs were selected. Relevant review articles and original research were used when appropriate and applicable to PWDs and their caregivers.

### Main message

There are several frameworks that attempt to organize the important experiences described by patients and caregivers. Prorok et al reviewed the qualitative literature on the health experiences of PWDs and their caregivers.<sup>8</sup> Out of 46 studies found, 7 involved patients, 25 involved caregivers, and 14 included both groups. The reviewers identified 5 themes, used as headings below, that reflect the experience of many dementia patients: seeking a diagnosis, accessing supports and services, addressing information needs, disease management, and communication and attitudes. Other reviews identify similar themes but focus more on an individual's change in function and quality of life and his or her responses to these challenges.

#### Seeking a diagnosis

*Given the lack of response of my symptoms to antidepressants, I was referred to a psychiatrist. His surprising diagnosis was not depression but dementia! I was then referred to a sleep clinic (where test results showed I did not have sleep apnea), a neurologist (who ordered a computed tomography scan), and a geriatrician (who ordered magnetic resonance imaging). The diagnostic process took almost 2 years.*

The diagnostic process can be lengthy and frustrating.<sup>8</sup> Earlier diagnosis seems to be associated with easier transitions and might delay need for a move from home.<sup>10</sup> Receiving the diagnosis can be a shock or a relief to patients, and disclosure is an important part of management. There are recommendations for content we should include when disclosing a new diagnosis of dementia to patients and family members (**Table 1**).<sup>11</sup> Physicians also need to take patients' preferences for information sharing and cultural differences into account.

*The FP is on the front line of treatment and diagnosis. The early diagnosis acts as a relief to PWDs and their family members. I found that no one wants to mention the word dementia in the early stages of investigation. There is a stigma attached to it. The PWDs will be in denial, thinking that theirs is a hopeless case just waiting for the undignified end in a nursing home. It is important for FPs to displace this stigma because there is life after a diagnosis. Active management of the disease can prolong the quality of life.*

*For many people, it can take more than 3 years from first symptoms to diagnosis of dementia. Denying and delaying does not do anything to alleviate the fear and worry that the patient has. A dementia patient cannot fully be an advocate for himself or herself.*

The presence of measurable cognitive deficits without clear effect on function is termed *mild cognitive impairment*. Although it is easily defined, determining if and when mild cognitive impairment progresses to dementia is often challenging and can make the diagnosis more complicated for patients and physicians.<sup>12</sup>

**Accessing supports and services.** Patients and caregivers often report a lack of knowledge of supports and services on the part of health professionals, resulting in delays in access once a diagnosis is made.<sup>8</sup> Although non-FP specialist services are viewed positively, there is often a long wait for evaluation in memory clinics and similar services, which leads to frustrations for patients and physicians.<sup>13</sup> A Canadian study found that FPs recognize the importance of support services but are not knowledgeable about local options and believe that coordination of resources is better done by other organizations.<sup>13</sup> It might be necessary to refer to or collaborate with other professionals to organize supports and services (eg, social workers for financial matters, case managers for home care, psychogeriatric nurse or psychiatrist for behavioural and psychological problems).

*The FP should have an up-to-date list of all the supports and services that are available, as well as their costs. I believe that this is important because so many PWDs have had to give up their employment and their income is greatly reduced. This disease puts financial strain on*

**Table 1. Strategies for disclosing a diagnosis of dementia:** *The diagnostic disclosure should not be a one-time event. Clinicians should aim for an evolving and dynamic process, including predisclosure preparation; timely, individualized, honest, and sensitive disclosure; and educational and supportive interventions after disclosure.*

DIMENSION	STRATEGIES
Predisclosure preparation	<ul style="list-style-type: none"> <li>• Develop a rapport and explore knowledge, beliefs, and perceptions</li> <li>• Develop insight into patient and family needs</li> <li>• Respect autonomy: ensure meaningful involvement of the PWD by asking questions such as "What do you think caused the change in your memory and thinking?" or "What do you suspect the results of our testing might show?"</li> <li>• Help develop insight: explore discrepancies in knowledge and reduce gaps in understanding</li> <li>• Titrate information: consider background, level of knowledge, cognitive ability, and emotional readiness</li> </ul>
Meeting information needs	<ul style="list-style-type: none"> <li>• Maximize comprehension using careful wording, "talk-back" approach, and written information</li> <li>• Provide comprehensive information including diagnosis, areas of uncertainty, expectations and treatment options, and community resources</li> <li>• Follow up after disclosure to review information provided, clarify goals and expectations, and reinforce linkages with community services</li> </ul>
Meeting emotional needs	<ul style="list-style-type: none"> <li>• Explore emotional reactions                             <ul style="list-style-type: none"> <li>-There might be a range of emotional responses to diagnosis</li> <li>-The PWD might have difficulty processing information and expressing emotions right away</li> <li>-Pay attention to cues and reflect back to the patient: "I imagine this is difficult news" or "You seem to be quite shocked by the news." Silence is a common reaction to the shock of hearing the diagnosis</li> </ul> </li> <li>• Respond to emotions in an empathic manner</li> <li>• Foster a sense of hope and meaning</li> <li>• Be positive, but avoid the temptation to minimize seriousness                             <ul style="list-style-type: none"> <li>-Tell the PWD that many aspects of "self" and brain function are preserved until later stages</li> <li>-Encourage a proactive response to diagnosis and timely future planning but reassure the PWD that decline is rarely rapid and there is time to adapt to the illness</li> <li>-Reaffirm your commitment to ongoing care</li> </ul> </li> </ul>

PWD—person with dementia.

Adapted with permission from Aminzadeh et al.<sup>11</sup>

*all people, even if they are elderly. Once you stop driving, for example, and there is no public transportation where you live, then the cost of getting around is substantial (both in time and money).*

*The Alzheimer Society is a good resource for patients, families, and FPs. The Alzheimer Society is aware of what each locality offers. It also provides support and education sessions for both PWDs and their families or caregivers ([www.alzheimer.ca/en/About-dementia/For-health-care-professionals/first-link](http://www.alzheimer.ca/en/About-dementia/For-health-care-professionals/first-link)).*

**Addressing information needs.** The type and amount of information provided to PWDs is an important issue for patients and physicians. Patients and caregivers report having to "push" for adequate information and appreciate clear communication, including written information. Common topics of importance include cognitive testing, medications, disease progression, financial and legal matters, and behaviour.<sup>8</sup> Caregivers report that their primary sources for information are the physicians but often note that FPs are more likely to discuss medications than topics such as course of illness or long-term planning.<sup>14</sup>

*The more physicians can learn from PWDs and their families, the better their understanding will be. How can a "normal" mind ever understand how foggy and scrambled the mind of a PWD is just by reading about it? Although each PWD has many similarities with other victims, there are also lots of differences. People in the early stages really need to know about their disease. There are education sessions put on by local health authorities, the Alzheimer Society, and others. There are books written by PWDs for PWDs. Family physicians and other specialists can also be a source of education, but always remember that the PWD needs things put in everyday language and sometimes the simpler the language, the better. I have found that my support group with the Alzheimer Society provides a wealth of information. As we talk about what is occurring in each of our lives, we often describe the same things and know that it is not just our imaginations running amok. The Internet can and does provide education. There are sites that are not reliable and could perhaps give false information and hope.*

*Physicians should ask about legal matters such as power of attorney, living wills, and personal directives. These can provide patients' voices when they can no longer speak.*

**Disease management**

Donepezil was prescribed for me by the geriatrician. Within days symptoms were reduced but it took a few weeks to feel the full effect. As the dosage was regulated my life became more manageable. Since my diagnosis in 2009 I have responded well to medications. The donepezil dosage was increased and at the end of 18 months had topped out and plateaued. Galantamine was tried, but my symptoms did not respond. My symptoms proved to have a good response to the rivastigmine patch. Currently I am using the 5-mg patch and leaving it on for 48 hours, as well as adding a new one at 24 hours. This is equivalent to a dose of 7.5 mg.

Caregivers and patients note they often feel the need to initiate discussions about management issues such as safety, driving, and medications. They noted also that the primary care providers' knowledge of dementia was a big factor in the perceived effectiveness of disease management.<sup>8</sup> Not all patients' symptoms of Alzheimer disease respond as well as Faye's did to medications but patient and family perceptions are crucial for FPs in gauging symptom response. Small functional gains, such as being more independent in dressing, can improve the patient's self-esteem and ease burden for caregivers. Some words of wisdom from Faye on disease management are provided in **Box 1**.

**Communication and attitudes**

My FP has been my doctor for more than 30 years so he knows me very well. His patience in listening to me was exemplary, especially when I could not communicate my thoughts as I once could. He not only relied on what he saw but also spoke with my family. I was seeing him on a weekly basis in the beginning and then semimonthly; now I see him monthly. We have conversations on a

**Box 1. How Faye manages her Alzheimer disease**

Here is some advice for patients about disease management:

- Take medications as directed by your doctor. Do not try to self-medicate. Questions should be directed to your FP or pharmacist. There are many gadgets to help you remember your medications (eg, blister packs, daily or weekly containers, timers)
- Eat a healthy diet
- Get both physical and mental exercise
- Get a good night's sleep. Your brain is working twice as hard as it did before just to keep things out of the fog, and this actually tires you physically
- I use lists (I never had to before), timers (eg, when I use the stove or iron), sticky notes and labels, and datebooks (I write everything down)
- I rely on old habits and routine, although lately this has been more difficult

variety of topics and I know he is using those to test my thought process and memory. He listens to all of my concerns and never do I feel neglected or rushed to leave. I know that he has taken the time to investigate the disease of dementia and all the ways it might appear, and how it disables not just the person but the family. I am not saying he is an expert in this disease but I believe that he has taken the time to be a bit better informed. I continue to attend the geriatric clinic. My medication is now prescribed by my FP but with the recommendations of the geriatric specialists. The FP believes that he is more familiar and knowledgeable about the medications now.

Communication and attitudes are important to patients and caregivers throughout the continuum of illness. The FP's willingness to seek input from the patient was viewed positively. Not surprisingly, physician sensitivity, respect, and attempts to preserve dignity were identified as important and poor communication skills were identified as a barrier to treatment success.

*The FP's attitude (kind, understanding, and, above all, honest) can change a person's outlook on dementia. The words that are spoken and the way they are interpreted are about that person's life and quality of life. If you find it difficult to speak openly with your FP, or that he or she does not listen or have time, then find another one! A support group helps.*

An area of care that intersects with all these themes and is sometimes misunderstood by families, patients, and physicians too, is the terminal nature of Alzheimer disease.<sup>15</sup> Mortality is related in part to age, but a palliative focus might be appropriate for people with advanced dementia regardless of age.<sup>16-18</sup> Discussion of power of attorney designation and advance care planning should happen as early as possible in the course of illness, while the person is capable. It is important that physicians, patients, and substitute decision makers are willing to discuss evolving goals of care as the illness progresses. With severe dementia it is likely that the substitute decision makers will be highly involved, so their understanding of the patients' perspectives is crucial.<sup>19,20</sup>

*[As an Anglican priest] I have walked several journeys with family members who have had dementia or cancer. I have witnessed their pain (physical, mental, and emotional). I have seen families who for no other reason than guilt and obligation continue to visit nursing homes, even when there is no acknowledgment or conversation. I have done a lot of thinking about the end of life during my adult years. These thoughts and ideas are not spur-of-the-moment things. I have searched my beliefs and love for my family before I came to these conclusions. They are my personal decisions and I realize that there are people who will not agree. We*

### Selected quotes from Faye

**PWDs and their family members must be their own advocates.** The age of relying totally on any doctor for information, available treatments, alternatives, etc, is over. Begin by educating yourselves and asking questions, especially to FPs. They are the ones who know you best and can help determine your best options

**Medication worked for me.** I found that once the symptoms of dementia were eased by medication, I was able to regain many aspects of my former life, although with some changes and modifications

**I am patient with myself.** There are some things, such as reading and following detailed instructions, that cause more frustration for me than enjoyment, so I have given them up. I continue to do crossword puzzles. There are answers to the clues that float around in my head. At first I would dwell on trying to retrieve them but now I am more patient with myself and let other cues and clues help my memory. And although they take longer to do, I find that they get my mind working in some semblance of order

**Spirituality is what comforts you; what calms turmoil in your heart.** Spirituality can be anything [such as] enjoying the outdoors (a beach, gardening, walking, bird-watching, sitting on a swing, meditation, yoga, etc). Spirituality puts a song in your heart and lets you dance through the bad days with hope for a better one. It eases anxiety and relaxes both the mind and body. To become lost in your favorite pastime, even for a short time, revives and redirects the turmoil in the mind. I firmly believe that there should be some part of each day given to some form of spirituality

**I have no problem with entering long-term care when it becomes too difficult to stay at home.** I do not want my family to give up their lives to "mama-sit." They have their own families and lives to live and I do not want them to give up everything to care for me. I know they would in a heartbeat. I can have an enjoyable life within a long-term care facility, many of which are like homes now. I would be able to go out and visit with family and friends and vice versa. I have made my wishes known that I do not want sympathy or guilt-ridden visits

**I have lived my life well.** I think I have made the best choices for myself and my family. I choose to die the same way. My faith gives me the confidence to not be fearful of death and to prefer it to come later rather than sooner. I love life. I live each day with enthusiasm, cherishing every moment regardless of what it holds. Someone once said, "Yesterday is history, tomorrow is a mystery, today is God's gift; that's why we call it the present." Celebrate it! Celebrate what is right in my world!

PWD—person with dementia.

*each have our own thoughts on this and probably the only thing we can agree on is that we want to be treated with love and respect. My thoughts and desires have been discussed with my children. They understand my reasoning and are accepting of them. I am strongly in favour of quality of life over quantity of life. Life is not counted by the number of years but what you put in those years.*

### Conclusion

Family physicians play a crucial role in dementia management. Patients and caregivers identify important management issues in the realm of diagnosis and disclosure, supports and community resources, information sharing, disease management, and attitudes and communication skills. Considering management in the context of these themes and trying to understand the experience and perspectives of PWDs and their caregivers will help physicians provide the best care.

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#### Contributors

Both authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

#### Competing interests

None declared

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