

Memory and cognitive decline: Family challenges

By Carol Edwards, RN, GCM

From observations of both my clients and my father, who was diagnosed with Pick's disease in the early '90s, I know that dementia and cognitive decline can bring out both the best and the worst in families.

Family members who play a large role in assisting with and organizing care can become stressed or “burnt out” during a disease’s duration, which typically lasts approximately 10 years. Even those who play a smaller part do not remain immune to the affects of the disease. In short, dementia can either make or break the person and the family.

Risks of the disease

You may notice certain symptoms in your loved one, such as memory loss, a change in personality, difficulty expressing him or herself, declining spacial awareness and executive functioning (e.g., the ability to plan and think abstractly), eating disorders and affects on the ability to take in and absorb food.

The biggest difficulty is the inability of your loved one to assess and report these changes, since they are often subtle. They can, however, become more acute at an alarmingly pace, especially in the presence of an infection. This sometimes results in your loved one ending up in the emergency department, which is when things get really complicated and an inexperienced caregiver can lose control of the situation.

Diagnosis and treatment

Today, cognitive decline can often be detected early. Brain scans can assess the volume, metabolism and cerebral blood flow to key brain regions, and important chemicals can be measured in the spinal fluids, blood and urine. These investigations are often performed in combination with memory tests and other clinical and neuropsychological assessment tools.

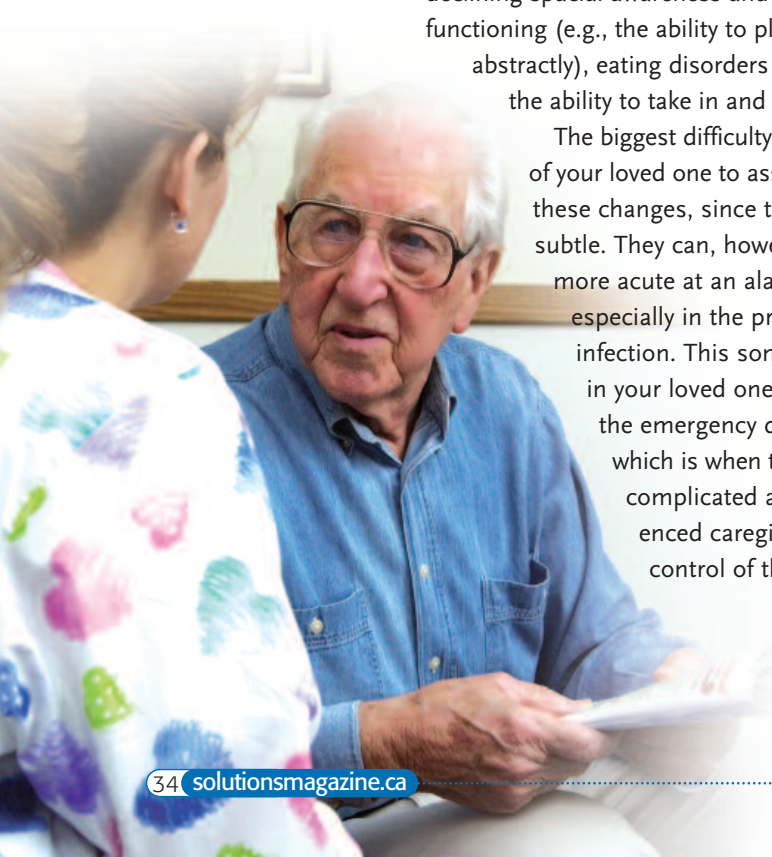
The latest hope is to find medications that not just slow disease progression, but actually stop dementia and related diseases before damage occurs in the brain. However, these are still some years away.

Memory-enhancing medications are often added to treatment during the disease process. The geriatricians I work with are very specific about the timing of such medications and sleep patterns, since they can affect the ability of the client to function during the day.

What kind of help?

Through my geriatric care manager practice, I have observed that it is extremely difficult for a family member to manage cognitive decline and dementia care single-handedly. The process is so complex that even those who are well informed will inevitably miss symptoms.

Typically a general practitioner (GP), geriatrician and other specialists will assist with the diagnosis and monitor disease progression. Generally, the geriatrician, makes recommendations and monitors the interactions of all medications, while the GP monitors all other





treatments as the disease develops.

However, this is only the smallest part of an ongoing and relatively complex process requiring frequent, accurate and timely supervision and assessment. I would also recommend the assistance of a nurse geriatric care manager or case manager who is familiar with the process. He or she will be able to help families with advice on what to report to a physician.

The role of the caregiver

One of the most important tasks for caregivers is making the “dots connect” in terms of the reporting symptoms and anticipating risk factors for a worsening of illness.

The overwhelming factor of dementia is that symptoms occur concurrently. Changes are constant and require adjustments from both the client and the family.

For this reason, I strongly recommend the assistance of a personal support worker. If well trained and managed, personal support workers can help clients by replacing their memory, cuing them to perform daily activities of grooming and feeding, and providing other assistance with bodily functions. There is no end to the quality of life that a skilled caregiver can bring to the cognitively impaired client. In fact, what they are doing is often covering for the clients’ deficits.

I cannot overemphasize the importance of the geriatric care manager or registered nurse in this process. Nurses assess, manage and monitor. They guide elderly people, their families, and their caregivers and assist physicians throughout the care journey.

Relocation

Most physicians, based on their onerous workload, will recommend transfer to a facility such as a nursing home that specializes in caring for clients with cognitive decline. While this can be the best option for families, it is sometimes not best for the client. A strange environment with no support from family or familiar people can cause much distress.

If transfer to such a facility is considered to be the best option then I highly recommend engaging private care, since the facility staff cannot personalize care for each and every client. Although such private care can be expensive, it is often well worth the peace of mind that it brings.

Changing the face of the disease

Alzheimer’s disease affects more than 26 million people around the world. Despite years of research, only a few treatments against the memory-robbing disease have been found and none of these can halt its advance.

An important issue is the public’s attitude toward the disease and its consequences. With our aging population it is timely to discuss dementia, consider the costs associated with the care of people with the disease and encourage both seeking a treatment and embracing the quality of life that can be achieved by people with dementia and associated diseases. ●



Carol Edwards, RN, GCM, is President of Careable, Inc. She can be reached at carol@careable.com or www.careable.com.

“The key is patience. You get the chicken by hatching the egg, not by smashing it.”

H. Gilasgow

5 best personality adjustments for family caregivers:

1. Increase your understanding and tolerance.
2. Give yourself time to process information before acting.
3. Advocate for your loved one.
4. Laugh when you get the chance. Try to see humour in difficult situations.
5. Appreciate the goodness in others.