**Dimensions of Dementia**

by Jon Caswell

Dementia is not a nice word.

“In the beginning, when the doctors told me that my mother would have dementia, I got angry,” Sybil Ingram-Campbell said. “That bothered me for years. I hated associating that clinical title with her. She’s a nice person, she’s not ‘demented.’ I’ve learned to live with it over these 11 years since her stroke, but we need other words.”

Sybil, 47, and her mother, Louise Ingram, 75, both live in Atlanta, Ga.

Dr. Marsel Mesulam is a neurologist who directs the Cognitive Neurology and Alzheimer’s Center at Northwestern University in Evanston, Ill. He defines dementia as “progressive brain disease that interferes with a person’s ability to carry out daily living activities because of cognitive and behavioral abnormalities.”

Dementia may be one condition, but it has multiple causes: Alzheimer’s, primary progressive aphasia, development of Lewys bodies, vascular disease. Dementia is thought to affect as many as 50 percent of people over 85. Alzheimer’s is the primary cause, and this kind of dementia is always progressive, though some medications may slow the cognitive decline.

Vascular dementia can be caused by a single stroke, though it is more commonly the result of multiple strokes (multiple infarct dementia) or TIAs. Stroke dementia is not always progressive, particularly if the underlying cause of the strokes or TIAs can be identified and treated.

Grace Mitchell had vascular dementia as a result of three strokes. Her son Kip took care of her at his home in Myrtle Beach, S.C., for 13 years until her death in 2004.

“My mother had three strokes, maybe four,” said Kip, 46, who is the operations manager for a medical alarm company. He is also a trained EMT. “She had two hemorrhagic strokes and one ischemic stroke. The first one was in 1991 when she was 62. Her short-term memory got worse with each one. Aricept stabilized her, but she didn’t improve. After the third one she was alone in the bathroom for six hours. After that she was diagnosed with dementia.

“She could hold her own on the memory tests, but she still had episodes of odd behavior. For instance, right after Christmas one year she threw away all the clothes we’d given her.”

Louise Ingram had a hemorrhagic stroke when she was 64; the doctors gave her a 3 percent chance of living, and that would only be on a ventilator, in a vegetative state.

“They said she wouldn’t live 96 hours, but now she can carry on a conversation,” Sybil said. “Of course, she can’t remember it. And she can walk now and no one expected that.”

In addition to caring for her mother, Dr. Sybil Ingram-Campbell is a health scientist with the Centers for Disease Control and Prevention, and she understands the medical
“This experience has deepened me spiritually. I’m a trained scientist, but if I had any doubts about the Creative Spirit, this experience has put them to rest.”

Sybil Ingram-Campbell and her mother Louise Ingram; photo by Greg Mooney, Atlanta Photographers, Inc.
issues involved. “If you looked at her chart, you’d say ‘why isn’t this person dead?’ But when the doctors meet her, they are always surprised, and they want her to do ‘tricks’ on command.”

Dementia encompasses an array of symptoms. “The spectrum is very large,” Dr. Mesulam said. “In some people, it’s a loss of memory; in others an impairment of word finding. Some have visual disorientation, while others have impaired judgment and insight. They can’t tell right from wrong.”

“My mother’s first symptom was short-term memory loss,” Kip said. “She moved in with me six months post-stroke, and she didn’t have any functional impairments. She could walk and fix her own meals. She had left-side weakness after the second stroke two years later. The memory problems got worse, and she developed this obsessive/compulsive thing where she’d start trying to call my sister, and if she wasn’t there, she’d call every two to three minutes for hours. There would be hundreds of calls.”

For Sybil Ingram-Campbell the change in her mother’s condition was overnight. When Louise came out of a two-week coma after the stroke, she was different. Over the years, brain images have shown a buildup of “white matter plaque.” Healthy brain tissue is called “gray matter.” White matter is an indication of cellular or tissue death, and when it accumulates into plaque — sticky, opaque stuff — it inhibits normal neuron firing.

Because Louise can’t be left alone, she stays in a nursing home during the work week and comes home with Sybil every weekend. “Mother’s dementia has not developed in the stereotypical way,” Sybil said. “I have her in a locked-down area because there are supposed to be structured activities there, but she has escaped twice by talking people into opening the locked door. I don’t know how she gets away because she doesn’t walk fast. She uses a walker. She wants to go back to Chicago.

“And that’s what’s interesting to me. The textbooks say people with dementia don’t have desires they can act on. So when Louise doesn’t act like the textbook says, they don’t know what to do with her. She has a sense of humor. She reads. I wish I could put her somewhere they would encourage her to do the things she can do as opposed to always trying to ‘manage’ her.

“I was told to expect a 180-degree change in Mother’s personality,” says Sybil, “to learn to deal with a new person. In Louise’s case, she’s a lot more pleasant and flexible. Now anybody can work with her. I see a side of her that I wish had been there when I was growing up. She was stern, not very affectionate.”

“Looking back, if I had the choice to do it over again, I would do it again without any hesitation.”

Grace Mitchell always enjoyed spending time with her grandchildren.
When Rosemary Horan developed dementia after several strokes, her daughter Patricia Latham, an attorney in Washington, D.C., discovered that many of her friends were in similar situations with their parents. Determined that others could learn from their experiences, Patricia worked with neuropsychiatrist Jean Posner of Baltimore to develop “Caring for Persons with Dementia,” an eight-page pamphlet of practical advice on issues like communication, legal competence and coexisting physical disabilities. An excerpt follows:

**Q:** Are people with dementia competent to make decisions for themselves?

**A:** Some are. Some are not. A neurologist or psychiatrist can evaluate and advise regarding competency.

**EXAMPLE:** A person with short-term memory loss alone may be quite capable of making financial and personal decisions. On the other hand, a person with severe impairments in broad areas of mental functioning may not be competent to understand relevant facts and make rational decisions.

**Q:** Can a person with dementia execute a valid Medical or General Power of Attorney, Living Will, or Will?

**A:** The answer depends upon the type and severity of the mental impairment. If the person is not able to know what he or she is doing by signing the document, then there is a lack of the necessary capacity. If the person does know, then there may be requisite capacity even though the person may be confused about time and place. Some courts have found certain individuals with dementia, caused by stroke or Alzheimer’s disease, to have the necessary capacity and to be competent to execute such documents. Witness testimony as to what the person understood, at the time of signing, is often important. The opinion of the treating physician may also be helpful.

**EXAMPLE:** In one case, a woman with Alzheimer’s was found to have sufficient capacity to execute a valid will because she knew the value and contents of her estate and to whom she desired to leave that estate, even though she was confused about her current living arrangements.

**Q:** What should you do if you have expressed your frustration or anger to the person with dementia?

**A:** Caregivers are often horrified at the anger and frustration they feel at times. Such feelings are a common experience for caregivers. Express your feelings, not to the person with dementia, but to a trusted confidant. Realize that it can be difficult to care for a person with dementia and that even a good person may become impatient at times. No one is perfect. If you have said something in frustration or anger to the person, catch yourself as quickly as possible and say that you are sorry. Try not to feel guilty or to reproach yourself. Turn the conversation in a positive direction. Let the person know that you enjoy visiting, so that the person does not come to feel that he or she is a burden. You might also praise the person and express your pride in the person’s accomplishments and efforts.

To download a free copy of the entire pamphlet, visit www.strokeassociation.org/strokeconnection.
Because of her work schedule, Sybil can’t leave Louise at home.

“At first there was enough insurance money for a private-duty nurse. When that ran out I had to enlist care because I couldn’t leave her at home. I put her in a nursing home, and she stays there from Sunday night till Friday afternoon. I visit her almost every night after work, usually for two to three hours. Then I pick her up and keep her at my home Friday night through Sunday evening. This is quite a financial commitment. I don’t have any retirement savings. If she’d had long-term care insurance it would have made it a lot easier. I recommend everyone get long-term care insurance for their parents.”

Sybil has made a number of changes to her two-story home, which she shares with her new husband, Robert Campbell. “We put a lift in because I wanted her bedroom on the same level as the master bedroom because she wanders at night. I put baby speakers in her room so I can be aware of what she’s doing. In the bathroom we added a booster seat and grab bars in the shower so I can bathe her while she supports herself.”

Sybil thinks that her mother’s memory loss works to her advantage in many ways. “Mother doesn’t acknowledge her stroke in any way,” she said. “She doesn’t remember anything — no doctor, no hospital, nothing about being ill. She thinks she is going to the nursing home to do therapy, and because she knows I’m coming back to get her on Friday, she’s okay.

“She thinks of my home as her home, but she understands that I have to work. Sometimes on Sunday she doesn’t want to go back. I have to start talking to her about two hours before we have to leave. When she asks why she has to leave, it just tears me apart.

“She still wants to have a purpose wherever she is. When I put going to the care facility in the context of someone waiting on her because they’re going to do therapy, she calms down.”

“After Mom’s savings were depleted,” Kip said, “she qualified for a long-term care program here in South Carolina. It provided a nurse’s aid or home assistant, but it had a long waiting list. Our application was finally approved, but I wasn’t there the day they came for the evaluation, and Grace told them she didn’t need it. She did get Meals on Wheels, and that turned out to be the highlight of her day because they always brought dessert. We’re both diabetic so there weren’t many sweets around the house.”

Medications are another concern. In Sybil’s case, they have only recently discovered a combination of drugs that allows Louise to have more awake hours than asleep hours.

Kip had a different medication challenge with Grace: “One day I found about 30 pills under her placemat that she wasn’t taking and telling me she was. After that I started giving her her pills and watching her take them.”

As many challenges as there are in taking care of a patient with dementia, both Kip and Sybil believe that it’s been worth it. In many cases financial issues have to be worked out. As Sybil pointed out, long-term care insurance is a good thing for parents to have. Kip acknowledges that working part-time cost him quite a bit of money, but “the money is inconsequential. We had a lot of fun together, particularly before the third stroke. It was a mental, emotional and financial strain, but as an EMT I do things for people that I don’t even know, so I would have done anything in my power to keep her at home.

“It wasn’t easy, and we did butt heads occasionally, like over doing her therapy exercises. Of course, I wish I hadn’t yelled at her over this or that, but at the time, it was the best I could do.”

“Looking back, if I had the choice to do it over again, I would do it again without any hesitation. The one thing that I would change is probably ask my brother and sister to help out a little more. I think they have regrets now that they didn’t see her that much in the last few years of her life. They were always busy or something came up. At least those are regrets that I don’t have.”

“This has been quite a learning and character-building experience for me,” Sybil said. “I wish I could keep Mother home all the time, but it just isn’t possible because of my job and because that wouldn’t be best for her. This experience has deepened me spiritually. I’m a trained
scientist, but if I had any doubts about the Creative Spirit, this experience has put them to rest. I don’t think it’s good for us to separate science from religion. They coexist well and complement each other. That’s another lesson I’ve learned.”

Both Kip and Sybil have advice for new caregivers. “Make sure that you can get time for yourself — get a friend or neighbor to come over for a little while so you can have time to do things you want or need to do,” Kip said. “If you don’t take some time for yourself, you build up a lot of resentment. I used to walk on the beach whenever I could.”

Sybil said, “Between taking care of Louise and spending time with my husband, I don’t have a lot of time for me. My goal next month is to go to the spa for a few hours.

“Nobody expects this to happen, and there wasn’t a lot of guidance out there for me. That’s one reason I have connected with the National Family Caregivers Association. That has allowed me to learn from others or to teach others what I have learned.”

“Assistance really depends on what kinds of symptoms the patients show,” Dr. Mesulam said. “So everything starts with the clinical evaluation — how does the patient interact with his or her environment and the family? Then you can begin to develop a plan for how to respond.”