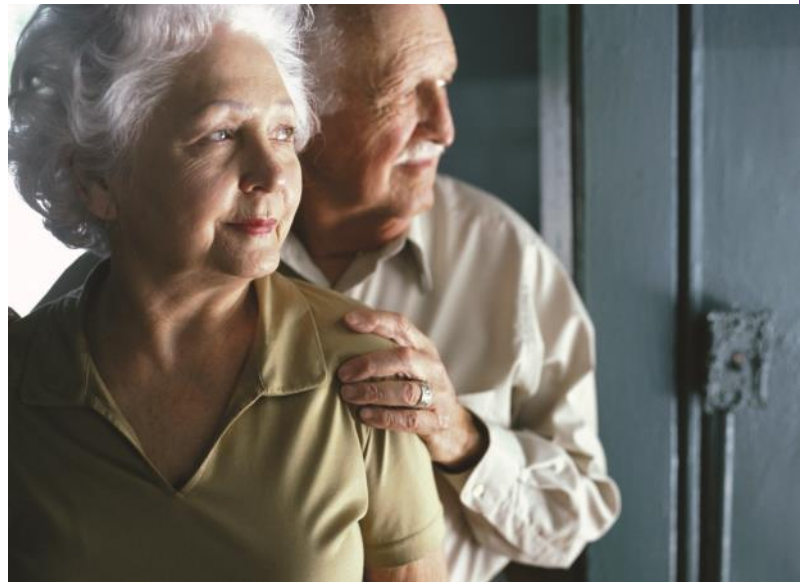


## The Light Beyond the Shadowing

By Luciana Cramer, Educator and Care Specialist



Rachel is almost despondent. Bill, her husband of 55 years, who has been a strong and independent man all his life, now follows her closely, like a shadow, everywhere she goes. He is right there behind her or by her side at all times, seeking her attention, asking repetitive questions, getting in the way of her activities. She does not have a single moment for herself, not a moment of privacy. If she is ever out of his sight he becomes anxious, agitated and confused. In his dementia, Bill is unable to understand her need for alone time. Rachel feels trapped.

Bill's behavior is known as shadowing, a recurrent subject brought up at caregiving meetings which causes much distress to family members. On one hand caregivers understand that shadowing is a common behavioral symptom of dementia and try their best to accommodate it. On the other hand, having someone trailing you around night and day demanding your attention can be disruptive and get on your nerves. And this behavior can go on for months, even years...

### Why do they do it?

People affected by dementia become increasingly disoriented as the underlying disease progresses. Common markers we all use to orient ourselves become ineffective. Compromised memory skills fail to provide information on what is going on and what is happening next. They feel lost. Calendars seem complex and therefore unmanageable. Notes previously used as reminders become meaningless or simply disappear. Dementia patients live in a world of uncertainty and confusion, and that's a scary world to live in!

Moved by the fear beneath the confusion, patients look for a way to feel safer and more grounded. Shadowing a trusted caregiver is their way of feeling secure. The caregiver becomes their anchor, providing the familiarity and reassurance they need to navigate their dementia-immersed world. Having the caregiver within sight makes them feel safe, and they do not know how to promote their own safety in any other way.

### Can shadowing be prevented?

Each patient with dementia is a unique individual with unique strengths, challenges and coping skills. Even though we cannot foresee who will shadow and who won't, it is expected that the confusion caused by dementia will at some point motivate one to shadow. Given the opportunity, most patients will shadow.

Caregivers can adopt preventative measures at the very beginning stages of the disease, before the impulse to shadow develops. Providing alternative means of orientation, uncomplicated and manageable enough to remain effective throughout moderate and later stages of the disease, may reduce the need for shadowing or, at least, alleviate its intensity.

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## Tips

- ◆ Say reassuring words every day and often, like a mantra — "You are safe. Everything will be OK. It's good that you are here. I love you." Your words should be simply stated, short, and always the same.
- ◆ Another idea is to make an audio tape of your voice (or any reassuring familiar voice). The tape can be a collection of short and meaningful stories from the person with dementia's past.
- ◆ In similar fashion, a videotape can be created. Remember, persons with dementia forget recent events, so you can play this audio or video tape again and again if it proves to be comforting. Familiar movies or music is another option.



## Tools

- ◆ You may want to install a childproof doorknob on the bathroom door or use a timer and reassure the person by saying, "I'll be back when the timer goes off."
- ◆ Utilize a day center so that your loved one will have more activities and more socializing opportunities.

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Establishing a daily routine is one such measure. Patients feel far more secure when routine activities are regularly observed: meals provided at the same times, morning and evening rituals observed, waking up and going to bed at habitual times, etc. It may seem boring to the rest of us, but routine is balm to people affected with dementia!

The same principle can be applied to furnishings and other household items. They should be simplified and kept unchanged. Avoid moving things around or rearranging items. Dementia and remodeling don't go together! Better not upholster that old chair, not change brands of cereal or shampoo, and by all means do not move the underwear to a different drawer.

A simple white board fixed to the wall can eventually replace all the notes and calendars as they become ineffective. (Use it to write timely information such as today's date, or *I'll be at golf until 2 p.m.*) Patients find comfort in knowing the information they seek is available at the same place whenever they need it.

Engaging friends and family members to provide companionship on a regular basis is also an effective way to prevent shadowing. If the people with dementia have multiple people with whom to interact and with whom they feel safe, they will be less likely to attach themselves to a single caregiver.

If you do not have enough friends and family members to assist with companionship, consider the use of a day center where they can be in a social setting, or hiring a professional caregiver to spend quality time with your loved one. Even if traditional caregiving duties are not yet necessary, such as help with dressing or medication, the additional companionship will help dissipate feelings of insecurity and the need to shadow.

### **My loved one is shadowing me, what can I do about it?**

After shadowing behaviors start, some of the above preventative measures may still be helpful, although implementing them at this point will be more difficult.

Other ways to reduce shadowing include involving the patient in engaging and familiar activities. These don't have to be structured activities with a group of people in a facility setting. Rather, they can be right in the home, as part of a daily routine. Try folding clothes or towels daily, raking leaves or working on a jigsaw puzzle. Don't forget to praise your loved one at the conclusion of the activity.

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*The caregiver essentially loses their own personal space and begins to feel smothered by the person with dementia. This leads the caregiver to attempt to separate themselves from the person with dementia physically, which then can lead to the perception of rejection by the demented person.*

- Carole B. Larkin, Geriatric Care Manager

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Snacks such as cereal or fruit can be used to occupy the person with dementia and distract them from following you. You can also provide headphones with a recording of their favorite musical selections. Music is very therapeutic for dementia

patients and familiar melodies and lyrics can be calming and relaxing. Additionally, some caregivers make a recording of their own voice speaking to their loved ones with reassuring words.

Remember, when dealing with shadowing you should address the motivating fear, not the behavior itself. Since no two dementia patients are alike, what works for one may not work for another. So be creative! Use your knowledge of your loved one's strengths, likes, and dislikes to formulate strategies to soothe them and encourage feelings of safety and security.

Finally, consider attending a caregiver support group. Whether in-person or online, support groups are a great resource for information about how to deal with the many challenges presented to dementia caregivers.