

WHEN CARE NEEDS CHANGE: HOW DO I KNOW?

By Kathy Bradley

In the wake of World War II, my father-in-law forged a prosperous career in business, providing a comfortable life for his family. In 1954, he built a charming brick home where he raised three children and supported his wife's pursuit of a teaching career after she returned to graduate school. Their retirement was filled with global adventures, and the family expanded to include four beautiful granddaughters. However, when my father-in-law suddenly declined from cognitive impairment into severe dementia, my mother-in-law was determined to honor his wish of remaining in their cherished home. With careful planning and gradual introduction of assistance, she fulfilled that promise until his peaceful passing in his own bedroom.

My parents, too, enjoyed successful careers, raised two children, and embraced a love for European travel. Decades ago, they made a different choice, investing in a "continuing care retirement community" (CCRC) to anticipate and address their future needs comprehensively. They enjoyed living independently on the campus of that community for several years. Nevertheless, challenges arose when my mother's severe dementia required more support than my father and in-home services could provide, necessitating her admission to the nursing home on the CCRC premises. She lived there for several years until her death.

Two families, similar life paths, shared experiences with dementia, yet two distinctly different scenarios. Neither journey was easy. So, how does one discern when changes in care are necessary, and how can you make the right decisions? Here are crucial questions to consider:

1. Are in-home services meeting all needs adequately?

- Ensure that in-home aides are available when your schedule requires their assistance. You should not be stuck doing the tasks you have hired them to do because aides are not available when you need them.
- Know that Medicare and Medicaid-regulated agencies should prioritize your schedule over theirs. Federal regulations require these agencies to meet the needs of the care recipient, based on the schedules and availability of the primary caregiver and other supports; not simply to schedule care at their convenience.
- Be aware that as long as the care recipient needs skilled services, like nursing or therapies, Medicare will pay for "non-skilled" services like personal care attendant to help with bathing, dressing, etc.

2. Do you have the resources to handle crises safely?

- Contemplate potential safety concerns, such as wandering or unsafe attempts to drive, and whether you can realistically establish sufficient preventive measures.

- Acknowledge the limitations of your resources, your surroundings, and your skills to manage the situation should a crisis occur, as inevitably it eventually will.
- 3. Can you handle behavioral issues emotionally and physically?**
 - Consider the emotional toll of caring for a loved one with dementia and honestly evaluate your capacity to manage aggression or other challenging behaviors.
 - Recognize your own physical condition (strength, agility, stamina) and limits on your ability to intervene safely in the event of behavioral outbursts.
 - 4. Are your expectations realistic?**
 - Assess if frustration is affecting your relationship and if your expectations align with the reality of your loved one's capabilities and your own.
 - 5. Is your relationship suffering due to role changes?**
 - Acknowledge shifts in roles and potential strains on relationships as caregiving dynamics evolve. Both caregiver and care receiver may struggle with these changes or simply be unable to adapt.
 - 6. Are you sacrificing your own health and well-being?**
 - Prioritize your health, recognizing that your well-being directly impacts your ability to provide quality care. No one can do it all.
 - 7. Does your loved one need more help than you can realistically provide?**
 - Recognize when external support or a different care setting may be necessary for the well-being of both you and your loved one. Knowing that you have limits is a strength, not a weakness.

In my personal experience, my mother-in-law's insistence on being the sole caregiver for her husband's severe dementia became untenable, risking her own health and her husband's safety. Introducing a caregiver, subtly at first, allowed her to "let go" gradually and share the caregiving; to focus on her husband's needs while maintaining her well-being.

My own parents had to access nursing home care when my mother needed more care than a home setting, even with additional supports, could offer. My father visited her faithfully every day throughout her remaining time, while round-the-clock staff provided the care she needed.

Every situation is unique. Every decision is hard. These tips can help focus on reality rather than emotion, perhaps making decisions clearer.

If, after honest reflection, the reality necessitates a change in living arrangements, stay tuned for our next installment, where we'll explore finding the right fit for your loved one's evolving needs.