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Residential Care Options: The Right Time

By Family Caregiver Alliance

Most caregivers are committed to keeping a frail or ill loved one at home as long as possible. Maybe they promised not to put the care receiver in a “nursing home”—the worst fear of many adults living with a debilitating illness. But there are many reasons why moving to residential care outside the home is not only necessary, but also the right thing to do. It is, however, a very difficult decision. Caregivers often struggle to care for a care receiver, waiting too long and compromising their own physical and emotional well-being, making the move even harder. There is not a “right” time—it is when you are ready or circumstances require it.

The decision to move your relative to a care residence is a very personal family decision. There are no clear-cut guidelines or answers for making this decision. Studies show that the main reasons for moving a loved one are: the need for more skilled care (tube feeding, wound care, intravenous medication, etc.); the health of the caregiver (back trouble, depression, cancer, etc.); dementia-related behaviors (such as exit seeking, sleeplessness, combativeness); need for more assistance (transferring, incontinence care, etc.); and debilitating mental health issues.

Other common reasons include discomfort with personal care (e.g. an adult child faced with incontinence care for his mother); fecal incontinence; lack of sleep; or the feeling that the care recipient no longer knows who you are. The change also may come after a hospitalization or medical crisis of the care receiver or caregiver, or when care plans change, such as when a loved one is no longer able to attend adult day care, or you are not able to find an appropriate home care assistant to hire.

When the level of care needed is so high that you, as caregiver, feel a sense of failure or inadequacy, when your physical or mental health is at risk, or when there are no rewards left for you in caregiving, then it may be time to consider moving your loved one.

Steps You Can Take

- **Be informed**—don't wait for a crisis or until you are totally burned out. Plan ahead, learn about options, explore choices in your community. This will increase your decision making control.
- **Have a family meeting**—with or without the care recipient. Talk honestly about the situation. Consider what each person has observed and what each person is willing to do to help. Be clear about all the caregiving tasks and responsibilities. Is hiring in-home help an option? What can be done if there is family conflict over the decision? (See FCA Fact Sheets: *Holding a Family Meeting*, and *Hiring In-Home Help*).
- **Get support**—from family, friends, extended family. It is hard to make this decision on your own and feel that you have all the responsibility for the decision. It may be hard to admit to your own limitations.
- **Attend a support group or get counseling.** Meeting with a counselor skilled in helping caregivers is known to help with decision making and reduce caregiver burden.
- **If the care recipient is able to understand and participate in decision making, talk with them about your limitations**—what you can and cannot do. Balance the positive and negatives for you and your loved one. Placement in a facility may be in the best interest of both of you.
- **Discuss money openly so that a decision is made consistent with what the financial situation is for the care receiver.** Explore options such as Medicaid. (See FCA Fact Sheet *What Every Caregiver Needs to Know About Money*)

- **Try a respite stay**—many facilities will allow someone to stay for a week or two to “try it out.”
- **What is your bottom line**—at what point would you feel you could have your loved one in a facility without feeling guilty? Everyone has their own turning points; they are neither wrong nor right.
- **Feelings**—this is hard. But difficult doesn’t mean wrong.
 - **Guilt**—means you did something wrong. Moving to a facility may be the best decision for the health and safety of the care receiver, as well as for you. Putting yourself first and taking care of your needs is not selfish. If you made a promise not to place your loved one, know that you made that promise at a time when you did not know what the future care needs would be. It was true at the time, but things change.
 - Feelings of ambivalence are natural—wanting to take care of someone and also wanting it to be over.
 - **Regret**—that you are in this situation and have to make this decision. It is not your fault; it is no one’s fault. Accept that you can’t control the disease or the course of the illness.
 - **Grief**—over loss of how you would have wanted life to be for you and your loved-one, loss of your role as primary caregiver, potential loss of your control and responsibility.
 - **Sadness**—it’s ok to cry and feel bad about the decision, but still know it is right and what needs to happen.
 - **Fear**—that your loved one won’t be taken care of the way you take care of him or her. This is true. He or she will be taken care of differently and will have someone who comes to work each day fresh and has the energy to be a caregiver, rather than you—perhaps exhausted and burned out, or maybe ill yourself. But you are the one who loves him/her and no one can replace that.
 - Thinking that going to a facility means he/she will die (sooner)—that it is a death sentence. But question your negative thoughts. Recognize it is regret and possibly guilt you are feeling.
 - **Uncertainty**—and second guessing. Did I make the

right decision? Could I have continued to care at home? Is this the right place for my loved one? What will I do when I am no longer a caregiver? Do I have a right to enjoy myself?

- **Responsibility vs. Obligation vs. Love**—all of these emotions play a part. Try to sort out which is influencing your decision.
- Special Concerns when the care receiver has dementia:
 - Caregivers are more stressed.
 - Long-term nature of illness makes it more difficult to decide when it is the right time.
 - Anger/frustration are common—at behaviors, at the illness, at the medical system.
 - Safety for yourself and for the person with dementia.
 - Finding the right facility takes more consideration.

Most caregivers experience less burden and their own well-being improves after placement, with less overload and less tension. But, you may also experience loneliness and the loss of your role as a caregiver, as well as depression. Remember: caregiving doesn't end, but it does change after placement (see the FCA Tip Sheet [Caregiving Doesn't End When Your Loved One Moves](#)). Husbands and wives often find it particularly hard. And, if you've had a conflicted relationship with the care receiver, it can also be especially difficult.

Remember: The time for placement is when you are ready.

Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

Email: info@caregiver.org

FCA CareNav: <https://fca.cacrc.org/login>

Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development

of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's, and other debilitating disorders that strike adults.

Residential Care Options: Five Tip Sheets

1. [The Right Time](#)
2. [Housing Options](#)
3. [Choosing the Right Place](#)
4. [Caregiving Doesn't End When Your Loved One Moves](#)
5. [Visiting Someone in Dementia Care](#)

FCA Fact and Tip Sheets

A listing of all facts and tips is available online at www.caregiver.org/fact-sheets.

Other Organizations and Links

Assessment of Need for Community Services & Out-of-Home Placement

Checklist from California Advocates for Nursing Home Reform (CANHR)

www.canhr.org/RCFE/html/rcfe_assess_need.htm

When You Are Faced With The Decision

<https://www.answers4families.org/>

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