

TRANSCRIPT

Leaving Home

Is it the right time to move your loved one with dementia to a care facility, or would they be better off living at home? This is one of the most difficult questions facing caregivers and their families—a question that usually doesn't arise until the caregiver reaches a critical point managing their loved one's care at home.

The question may be triggered by the emotional stress of handling behavioral issues, such as wandering or aggressive behavior. Or when physical limitations grow too difficult to handle within the home. For example, when loss of mobility requires a wheelchair, but the home isn't readily adapted for accessibility. Also, as your loved one's disease progresses and their needs become more complex and constant, the cost of home care will rise. When it reaches 24 hours a day, the costs can become overwhelming—another reason to consider community care.

These are just some of the challenges that drive caregivers to seek community care. No doubt, this decision can be fraught with great sadness and guilt. But I use the analogy of airplane oxygen masks. It might feel counterintuitive, but the reason we're told to put our own masks on first, before helping others, makes sense: We're no good to our loved ones if we collapse under the strain of their care.

So, how do we go about choosing the right facility or community for our loved ones? Where do we start? One way is word of mouth—from support groups, or the social worker working with your health care provider, to name a couple of possibilities. If you have a care manager, you can call on him or her to shepherd you through this process. There are also placement agencies that specialize in helping families navigate these decisions.

Fairly soon, if not immediately, you will need to start getting your affairs in order. All long-term care communities will require proof that an authority has been assigned to make medical and financial decisions on behalf of the person being placed. Terminology differs by state. The authority for medical decisionmaking can take the form of a health care proxy or an advance health directive. Financial decisions and the authority to release funds are assigned to a person with power of attorney. You can work on this while deciding the type of memory care facility you want.

A key factor to consider is the right level of care for your loved one. Some communities include both assisted living and secure memory care—an option for people with dementia and their aging spouse. Assisted living communities typically offer care services for people who are no longer able to live alone, but want to maintain a social, active lifestyle. They may feature group activities, outings, and restaurant dining, as well as help with laundry, housekeeping, and daily living, such as bathing, grooming, and medication management. Assisted living units usually make up the lion's share of these mixed-use residences.

Memory care communities are designed specifically for people with cognitive impairment and usually house between 50 and 60 residents. These communities typically offer both private and common areas, as well as outside areas for the residents to enjoy time away from group settings. The staff is usually trained to work with cognitively impaired people. Services vary but may include social hours, games, and activities to support motor and cognitive skills, as well as exercise.

A more intimate type of community, called care homes, is available in some parts of the country. As the name implies, these residences feature a home-like environment for 15 to 25 residents. Unlike most larger communities, care homes offer home-cooked meals, sometimes with customized menus, and the staff-toclient ratio tends to be higher. While not all care homes provide structured activities, residents may be able to

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bring in their own aides for specific services such as memory training and exercise.

Another consideration is the level of structure best suited for your loved one. For example, memory care communities typically offer scheduled programming from 8 am to 6 pm, whereas care home environments tend to be more relaxed, with the main goal being for residents to feel comfortable and at home.

Consider also the services the memory care community offers—such as physical therapy, occupational therapy, and transportation to appointments such as medical checkups. Many communities also include memory stimulation and cognitive therapy. How important are these to you and your loved one?

Finally, don't overlook the convenience factor. All other things being equal in terms of the quality of care, we suggest selecting the community that's easiest for you to visit.

After you've homed in on a community, you'll usually be given a chance to speak with the director or other coordinator, and observe how they interact with both residents and staff. This is important. This person will lead the team overseeing your loved one day in and day out, so you'll want to make sure you feel comfortable with their leadership and personal style.

It's also valuable to get the perspectives of the families of residents. Their opinions are just that, opinions, but you'll get an insider's view of life in the community, and whether it might suit your loved one. In terms of the actual accommodations in memory care communities, you should be able to visit the communal areas as well as the residents' rooms.

So you have chosen a community and negotiated the terms—and you're ready to make the move. As difficult as it may feel after spending so much time and energy caring for your loved one, it's vital that you allow for an adjustment period. Many memory care communities wisely suggest allowing the resident a week, or even two, to acclimate to their new surroundings and routines before visiting. If you have not already, this is an ideal time for you to join a support group the community may even offer one.

To help with the details of moving, if finances allow, you can hire a transition specialist who works with seniors to sort through your loved one's belongings, and help you decide what to bring, and what to sell, donate, or dispose of. These specialists are often skilled at patiently and kindly understanding the emotional issues that come up during this sensitive time.

Once your loved one has settled in, we strongly recommend staying actively connected with the community, and becoming an advocate to make sure your expectations are being met. Do not feel reticent. A safe, well-managed, resident-centered community will welcome and encourage your involvement. They will want to foster your relationship and curiosity with compassion. They will want to assure you that they honor your loved one.

Deciding on home care versus community care and finding the one that's right for you—can be a long and arduous process. The good news is there are many resources available to support you along the way. And in most cases, families who finally decide to place their loved ones in memory care often look back and wonder why they hadn't made the move sooner: Their loved ones are happier with their new home—and so are they. In other words, the hard work was worth it.

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