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Question #1:

When is the ideal time to move from living in one's own home to living in an Alzheimer's care facility?

I have been asked this question many times over the years. Every family member asks themselves these very questions: "Is it time? How will I know? What if I make the move too early?" There is no simple answer. Each caregiving situation is different, and how much care each person needs and their response to assistance is different.

It used to be generally thought in the senior care industry that the main trigger for placement is when the person becomes fully incontinent. However that is no longer felt to be the main reason. It is now believed that the trigger is when the caregiver simply can no longer provide the care, either because they are exhausted (most often the case) or the care needs have far outgrown what the caregiver can provide.

It is most common that a move is made when there has been an emergency situation, such as a fall resulting in serious injury, an episode of aggression or ongoing combativeness with personal care, or an episode of becoming lost. A move at this time is too late and the decisions are hurried and rushed.

Things to consider when deciding when is the ideal time to move from living in one's own home to living in a specialized Alzheimer's care facility:

1. Does the person sleep throughout the night? If not, then the caregiver is not getting appropriate sleep and their health is at risk.
2. Is the person resistive and combative with personal care, such as bathing and dressing? Is the caregiver at risk for injury?
3. Does the person refuse to take their medications on a frequent basis, and as a result their health is at risk or their behavioral control is compromised and this places an advanced risk of harm or injury to themselves and the caregiver.
4. Is the caregiver taking appropriate care of their own health? Are they going to the doctor for their preventative health screenings, or are they missing or skipping their own appointments because they can't leave their loved one long enough to make the appointment?
5. Is the person incontinent throughout the day and night, causing damage to the household furnishings, carpets, mattresses, and chairs?
6. If the person is incontinent, are they compliant with restroom assistance or are they resistive and combative and therefore placing themselves at risk for increased infections?
7. Does the person still recognize their home as their home, or are they asking "to go home"? If the person is no longer recognizing their living environment as the home they have lived in for many years, they are at risk for wandering out of the home.

8. Has the person become lost or wandered out of the home unattended, even to the front yard or backyard and could not figure out how to get back inside the house? This places the person at great risk for injury and if it has happened once, it will happen again.
9. Does the person recognize their caregiver as their spouse or adult child? Do they think there is a stranger in the house and this causes them to become upset and combative? When this happens the stress level of the caregiver is tremendous, and there are frequent power struggles between the caregiver and the person needing the care.
10. If the person is living at home alone and are confused to person, place, and time on a frequent basis, they are at great risk of getting lost, being taken advantage of, or wandering away.
11. If the person is calling their family members at all hours of the day and night expressing fear, anxiety, or confusion, they need to be in a more supportive environment.
12. Is the person sleeping all day in front of a TV or in bed all day due to lack of activity? They will maintain their skill level much longer if they are active during the day and their sleep patterns will be improved.

These are the top 12 reasons to consider when deciding when it is time to make a change. Most families report that they should have made a change much sooner.

Question #2:

In making the choice to move to a facility, what are the three most important factors that a family should consider?

1. Is the community a licensed and certified Alzheimer's or related dementia community? The amount of staff education and in-service requirements are much higher in a certified community. The facility is also allowed to take additional precautions to prevent wandering, and the activity programming is held to a higher standard.
2. Sometimes it is better to drive a longer distance to receive the best care rather than selecting a community that is closer.
3. Many times families are looking for a community where their loved one can remain until they depart this earth. Being able to stay until death does not have any impact on the daily quality of life and care the person will have or receive on a daily basis. And while there are many communities that may say they offer end-of-life care, this should not be the deciding factor. In fact, it is not common for the person to be able to remain in assisted living until they pass away, due to the state regulations that an assisted living facility has to operate under versus those for a nursing home. The decision of where to place a loved one should focus on how well the loved one will be taken care of every day and how well they will be engaged in their daily life today and tomorrow.

Question #3:

Once a person moves into a facility, what are some of the ways in which the family members can help make this transition easier?

1. Don't visit too frequently at first. Frequent visits can make it more difficult for the person to transition into the community and for them to adjust to the new routine. Frequent visits at first are also emotionally difficult for the caregiver.
2. When visiting, leave the purse in the trunk of the car and put the car keys in a pocket. When it is time to leave from the visit, it is common to grab the purse and keys, which is a big flag to the person that the caregiver is getting ready to leave.
3. Give hugs when you first arrive instead of when leaving. The less of a production at the time of exit the smoother the exit will be for both the caregiver and the person.
4. Ask the staff to help with a diversion activity so the person is occupied in an activity when the caregiver leaves.

Question #4:

In working with families that have waited too long, what do you see as the primary causes?

1. The entire family does not agree that placement is needed. This is most common with siblings when the primary caregiver does not have the support of the other siblings who do not manage the day-to-day care of the person. No one in the family truly knows the toll it takes on the caregiver, unless they are the direct caregiver.
2. Making promises that the caregiver cannot keep, such as "I promised Mom/Dad I would never put them in a facility".
3. The Caregiver is afraid their loved one will "never forgive them" or they will become "angry with them". It is fairly rare that the person is able to think in "cause and effect", so although they may be angry at first, this soon fades and the person doesn't really know who to blame.

It has been my experience that making the transition is much more difficult on the caregiver than the actual person who is receiving the care. The caregiver thinks they are "giving up the care" and "failing" when in actuality they are still the primary caregiver and decision maker. The difference is the facility is doing the work instead of the family caregiver. A transition returns the family dynamics back to a family relationship instead of a "working" relationship. Many families have expressed this has been a blessing for them.

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