

# Navigating Dementia Care: Important Questions for Caregivers



## Be Light Care Consulting

Choosing the right care community for a loved one with dementia is a significant decision that impacts not just the person in care but the entire family. It requires thoughtful consideration, research, and often, visits to multiple facilities to find the best fit.

When touring these communities and deciding on which one to choose, knowing the right questions to ask can make a world of difference in ensuring your loved one's needs, preferences, and comfort are adequately met. This guide aims to equip caregivers with a comprehensive set of questions designed to uncover the nuances of care provided at each facility.

Remember, the goal is not *to interrogate* but *to engage* in meaningful conversations that help you understand how the community can support your loved one's unique journey with dementia. The following list is a starting point. It's important to approach these tours with an open mind and a clear understanding of your loved one's specific needs and behaviors.

Keep in mind that care communities, while experienced, will be meeting your loved one for the first time. They will require time (and your insights) to truly understand and cater to the individual and unique needs of your loved one.

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In the questions beginning on the next page, you will see the **first bullet bolded**. This indicates the question I have deemed most important to ask in each section. You may find another question more relevant to your situation, *and that is okay!*

There also are not **right** or **wrong** answers to many of these questions! This dialogue opens up the opportunity for you to share crucial information about your loved one and set realistic expectations (for you and for the staff) about the care they will receive.

## Dementia-Specific Questions:

### Alzheimer's Disease:

- **Tell me about your understanding of Alzheimer's Disease.**
- My loved one's memory is very short. How do your staff deal with repetitive questions or storytelling?
- Tell me about how you handle when a resident asks over and over again to "go home".
- If my loved one asks about someone who has passed away, do you tell them the truth? How are situations like that handled?

### Frontotemporal Dementia (FTD or Pick's Disease):

- **Tell me about your understanding of FTD.**
- Is your staff familiar with FTD and do they understand the specific symptoms exhibited with this diagnosis?
- My loved one exhibits some behaviors that may seem "rude" or "mean" due to their impulsivity. They can't help it. Is your staff prepared to care for them despite this? Do they understand that this is a symptom of their disease and not a choice they are making?
- My loved one has difficulty communicating. How can I help the staff understand them better so their needs are met?
- I know my loved one is going to present differently than many others here. How can we make sure that his needs are not overlooked and staff are prepared to care for them adequately?

### Lewy Body Dementia (LBD or also known as Parkinson's Dementia or Dementia with Lewy Bodies):

- **Tell me about your understanding of LBD.**
- Is your staff familiar with LBD and do they understand the specific symptoms exhibited with this diagnosis?
- My loved one occasionally experiences visual hallucinations and can get very agitated or scared when this happens. Is your staff prepared to assist them in these moments? What is the plan?
- There are some medications that aren't recommended for individuals with LBD. Is the physician here familiar with this and will I be notified of any medication changes? *[the most common medication that this population is super sensitive to is first-generation antipsychotic medications, such as haloperidol (Haldol)]*
- My loved one experiences rapid eye movement sleep behavior disorder (RBD) which results in him moving a lot while sleeping and being very sleepy throughout the day. How can we make sure your staff is mindful of this?
- My loved one experiences tremors and difficulty walking. Is therapy available to assess them regularly to make sure we are decreasing their risk of falls?

### **Korsakoff Syndrome (aka Wernicke-Korsakoff Syndrome)**

Korsakoff Syndrome, often associated with Wernicke-Korsakoff Syndrome, is a chronic memory disorder typically caused by severe deficiency of thiamine (vitamin B1). It's most commonly related to alcohol abuse but can result from other conditions that affect nutritional uptake.

- **Tell me about your understanding of Korsakoff Syndrome.**
- Is your staff familiar with Korsakoff syndrome and do they understand the specific symptoms exhibited with this diagnosis?
- My loved one is younger than many of the other residents, how can we facilitate connections with others?
- My loved one often confabulates (tells detailed false stories) and has strong communication skills. Sometimes I worry that he will fool visitors or staff into allowing him to leave. How can we make sure this doesn't happen?
- My loved one has a past history of substance use and will occasionally ask for these items. How might you manage this situation?

### **Young-onset dementia (such as FTD or Early-Onset Alzheimer's)**

- **Tell me your understanding of young-onset dementia.**
- Is your staff familiar with young-onset Alzheimer's and do they understand the specific symptoms exhibited with this diagnosis?
- My loved one is younger than many of the other residents, how can we facilitate connections the others?
- Can you give me some examples of activities you offer that may cater to younger residents with dementia?
- How is care tailored for individuals who may be more physically active or have different needs than older residents?
- How do you involve the family in the care plan, considering the younger age of the individual and potential presence of minor children or dependents?

### **General:**

- **What kind of training does your staff receive about dementia? Is it hands on or virtual? Do they get tested on their knowledge? How often do they receive training: only once when they are hired or regularly? Who conducts these trainings and what credentials do they have?**
- Do they understand how different types of dementia present and the unique symptoms?
- What kind of accountability is there if they don't demonstrate good strategies?

## Facility:

- **What is the staff-to-resident ratio during the day and at night?**
  - Can I see the report of your previous state survey?
  - What safety protocols are in place to keep my loved one from walking out a door?
  - How often are the rooms cleaned?
  - What supplies are provided by you and what do I need to bring?
  - What are the qualifications, licenses, or certifications of your staff, especially those providing direct patient care?
  - What types of rooms are available and how much personalization is permitted?
  - What measures are in place for infection control and prevention and what quarantine protocols are in place?
  - Can you describe the emergency preparedness plans for the building, including fire safety and evacuation procedures?
  - Are there outside spaces available to residents? Can they access them independently?
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## Visitation:

- **What hours of the day can I come into the community to see my loved one and what flexibility exists if we have varying schedules? How do we check in?**
- Do you allow families to place cameras in rooms?
- Are there any limitations in who or how many people can visit?
- Are there any private rooms or areas available if we want to gather for a celebration?
- Are family members allowed to spend the night in a loved one's room?
- Can we take residents out for day visits? What about multiple-day trips?
- What is the protocol for bringing children or pets to visit?
- Is there support for long-distance family members who want to keep in touch with residents?
- Are there any items that we are not allowed to bring during a visit?
- Do you recommend families stay away after the resident moves in for a period of time? Is this a rule or recommendation and tell me a few examples of how this was either beneficial or detrimental.

## Communication With Staff:

- **If I have a concern about therapy, a nurse, a care aid, a housekeeper, the director of nursing, etc. who do I talk to?**
- How often will we meet to talk about my loved one's care? Can I request a meeting when it isn't scheduled? How much time do you need in advance? Who will be present during these meetings?
- Talk to me about communication of staff across shifts. For example, if my loved one is constipated on first shift, how does the person on second shift know?
- How frequently will I receive updates on my loved one?
- How can we provide feedback on our loved one's care? Do you utilize any technology or tools that are easy to use?
- Are language interpretation services provided for non-english speaking families?
- How are changes in policies, procedures, or staffing communicated to residents and families?
- Can you provide me with the contact information to the ombudsman for this community?

## Problematic Scenarios:

- **If my loved one starts demonstrating some adverse behaviors like refusal of care, resistance, or combativeness, what is the plan?**
- What is the process if my loved one falls? Am I notified? Are they sent to the hospital?
- What interventions are put in place for those who are at a high fall risk? Do they get a therapy referral?
- Tell me about in what situation you may initiate medication administration in response to adverse behaviors.
- Do you send people to geriatric psychiatric hospitals? What situation would result in this decision?
- My loved one loves to fidget and move things around at home. What do you have available to meet that need or will that cause a problem?
- What happens if my loved one becomes a danger to themselves, to staff, or another resident?
- What happens if a resident develops a pattern of refusing care like taking a shower or taking medication?
- How is the theft or loss of personal items handled?
- What is your policy in handling complaints from families?
- What is the process in handling situations where residents frequently enter into other residents' rooms?
- How do you handle conflicts or disputes between residents?

## Medical Care:

- **What criteria do you have for someone to live here? Is there a point at which my loved one might require more care than you can provide. If so, will you make us leave? How long will we have to leave? Will you assist us in this process?**
  - How long have you worked here?
  - Do you have in-house physicians? Who are they? How often do they come and is it in person or virtual? How can I get a hold of them? Do I have the option of choosing another physician?
  - Since my loved one gets up at all hours during the night, is there staff available to keep watch and how do they deal with that?
  - If a resident passes away, what is the process? How are families notified?
  - How do you coordinate care with outside medical providers?
  - How are medication administration and management handled? Are there limitations in how much staff can assist a resident with taking medication?
  - In the event of a medical emergency, what steps are taken? How am I notified?
  - How is palliative or end-of-life care managed for residents with advanced dementia?
  - What would deem a trip to the emergency room? Am I notified before or after that decision is made?
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## Therapy:

- **Is therapy available for my loved one? What disciplines are available (physical, occupational, speech therapy)?**
- Do they work inside this building or do they come in from the community?
- What red flags exist that indicate that a person may need therapy?
- If I think they need therapy, who do I contact? What is the process like for referrals?
- Will I be notified when therapy is started or discharged? How do I know about progress? Will they call to tell me or can I call and ask?
- Do all the medical providers collaborate and communicate about the care my loved one needs and receives?
- Can you show me where therapy is provided in this building? If there is no therapy gym, do they receive services in their room or in public areas?
- Can you describe how therapy is personalized for each resident?
- Are there additional costs to therapy?

## Activities of Daily Living (ADLs which include showering, toileting, dressing, etc.):

- My loved one can care for themselves partially right now but I know that they will change over time. What is the protocol when a resident needs more assistance with ADLs than they have been receiving? Whose responsibility is it to communicate that they need to provide more assistance than previously and how is that documented?
- If they need more help, will they get a referral to therapy?
- What are the bathing options here (shower, tub, bed bath), what time of the day is this done, and how often do residents bathe?
- If my loved one refuses to shower/toilet/get dressed/etc. what happens? Does another staff member try? Am I notified?
- What incontinence products and toiletry items are supplied by the facility and which am I expected to bring? Am I notified when they are getting low or do I need to keep up with that?
- Is there an expectation that they change clothing every morning and evening?
- Do staff encourage or assist with brushing teeth? How often does this happen?
- How do you assess a resident's ADL capabilities upon admission and throughout their stay?
- How do you ensure privacy and dignity for residents while assisting with personal ADLs, such as bathing and toileting?
- How do your staff encourage independence with ADLs? Do they allow the residents to do as much as the task as they can?
- What happens if my loved one becomes incontinent? What is that process like?
- If my loved one loses the ability to feed themselves, will your staff assist? Will they receive a therapy referral?

## Activities

- If a resident is bored during a time of day without a scheduled activity, what are their options?
  - Can I see your activity calendar? How closely do you stick the scheduled items on the calendar?
  - How are residents engaged, especially those who might not be interested in activities?
  - Are there activities available for residents of all cognitive levels and stages of dementia?
  - Are there any cultural or religious activities available to ensure the cultural diversity of residents is respected?
  - Do you take residents on outings? What level of supervision is available?
  - How many activities staff members do you have?
  - Are activities available on the weekends and in the evenings?
  - Do you have events where families can come and attend?
  - How do you invite residents to activities? What happens if they consistently refuse? What measures are in place for those who isolate?
  - How is resident feedback incorporated in planning future events?
  - Do you offer outdoor activities?
  - Do your staff provide room visits for one-on-one engagement?
  - Because my loved one has poor balance, will they be limited in what activities they can participate in? Are the staff trained in how to physically assist them to participate?
  - How does the facility celebrate holidays, birthdays, and other special occasions for residents?
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## Resident Experience:

- **Describe a typical day for a resident here.**
- How do residents call for assistance? What if they are unable to remember to push a call button? Do you work with them to train them in the use of the alert button?
- How often do you check residents throughout the day?
- Do you allow residents to nap during the day?
- Do residents spend most of the day out in the common areas or in their rooms typically?
- Do their rooms lock automatically? Will they be required to have a key to their room?
- How do you ensure each resident feels valued and respected in their daily interactions with staff?
- Do you facilitate friendships among residents?
- What feedback mechanisms are in place for residents and their families to suggest improvements or express concerns?
- What measures do you take to ensure resident safety without overly restricting their freedom?
- How do you accommodate and support the expression of residents' spiritual beliefs and cultural traditions?

## Food and Dining:

- **How do you handle situations where a resident refuses to eat or has a significant change in appetite or weight? Am I notified?**
  - Who creates the meal plans? Do residents have any say in the choices?
  - If they don't like what is served, do you offer other options to residents?
  - Can I bring in food to them? Can I leave food in their room?
  - Do you check the cabinets and refrigerator for expired items occasionally?
  - What if they have dietary restrictions? How is this accommodated, communicated, and enforced?
  - How do you identify if a resident is having difficulty with swallowing? How do you ensure residents with swallowing difficulties or other eating challenges receive appropriate meals? Are they given a referral for speech therapy? Is their food or drink modified in any way?
  - What steps do you take to make mealtimes engaging and enjoyable for residents?
  - What do you do if a resident gets up from the table without eating consistently?
  - Do you offer snacks and beverages outside of regular meal times?
  - How do you monitor and encourage adequate hydration and nutrition among residents?
  - Can residents have meals in their rooms if they prefer not to dine in the communal area?
  - How do you support residents who need assistance during meal times?
  - Can families come during mealtimes? Can we eat with our loved ones? Is there a cost for these meals?
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## Medications:

- **What do you do if a resident does not take their medications? Am I notified?**
- Who supplies the medications to the residents?
- Can residents bring in their own medications?
- Can a resident have an over-the-counter medication in their room such as eye drops or hydrocortisone cream in their room?
- If a new medicine is started late in the day, how quickly do you receive medication deliveries?
- Who administers medications to residents and what are their credentials?
- How do you ensure the accuracy of medication administration for each resident?
- What qualifications do staff members who administer medications have?
- What systems are in place for monitoring and managing potential side effects or adverse reactions in residents?
- How often are medication reviews conducted to ensure ongoing appropriateness for residents?
- What is the procedure for storing medications securely while ensuring they are accessible when needed?

- How do you accommodate residents who are on complex medication regimes, including those requiring injections or IV therapy? Can this be provided in this community?
- How are medications administered to residents who have difficulty swallowing pills?

This list is designed to be comprehensive but not exhaustive. Tailor your inquiries to match your loved one's specific situation and feel free to add any other concerns that come to mind. The right care community will welcome your questions and offer transparent, thoughtful answers that help you make an informed decision.