

Considering Assisted Living?

Strategies for Prospective Residents & Families



The Long Term Care Community Coalition

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Coalition of Institutionalized Aged and Disabled

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www.nursinghome411.org

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INTRODUCTION

Note to the Family

This guide has a special focus—promoting older adults’ rights to make decisions about their lives as they choose an assisted living setting. That’s why it speaks directly to older adults who are potential residents of assisted living. But it can also help you.

As a relative of an older adult, you may be helping to choose an assisted living residence for your loved one. Especially if your family member is struggling to make decisions due to cognitive impairment, you may be the unofficial decision-maker or even the legal guardian. If so, all the ideas here can help you as you use your judgement to guide your loved one’s life.

Say your mother is having difficulties due to dementia. There may still be times when her mind works well. She might not be able to make decisions such as whether to get cataract surgery, but she still may have strong clothing and food preferences. Even if her safety is your main concern, it is still important to honor her preferences at this stage in her life.

When visiting an assisted living, it is also important to know that the staff may view you, rather than your loved one, as the customer they want to please. An important part of your role is to ensure they focus on your loved one and their needs and preferences. You can help by encouraging them to get to know your loved one, telling them about their habits, preferences, or favorite activities. **The forms in this guide can help you identify and communicate your loved one’s needs and preferences.** [These forms can be downloaded or printed from the assisted living page of our website, www.nursinghome411.org/assisted-living-guidebooks/.]

Throughout this process, we encourage you to carefully consider and discuss with your relative what they need and want to continue living as independently as possible. Identify your common goals as well as issues on which you may disagree with each other. This will help make your time spent visiting and evaluating as useful as possible and help ensure that your loved one makes the best choice possible.

This Guide’s Purpose

If you or a loved one is considering moving to an assisted living residence, this guide is for you.

Assisted living residences (also referred to in this guide as “facilities” and “communities”) can be promising options for seniors because of their philosophy to promote resident independence and rights to make decisions while providing housing and tailoring services to meet individual needs and preferences. However, this promise is hard to fulfill. It is important that you understand the philosophy of each community you visit and how each will enable you to live your life the way you want.

The purpose of this guide is to help potential residents choose an assisted living community that truly fulfills the promise of assisted living: maintaining resident choice and autonomy in a home-like, non-institutional, environment.

This guide's purpose is to help you find a residence where you can achieve what many seniors want from assisted living: staying as independent as possible, maintaining control of your life, and remaining in your preferred residence, even if you become more dependent.

Important Notes on Using This Guide

This guide will help you evaluate your needs and preferences, and help you decide which facilities will suit you best. However, it does not delve into important issues such as evaluating contracts, costs, and admission/discharge rights. Because state assisted living industry requirements tend to be limited and there are virtually no federal requirements, it is critical for consumers to be informed and cautious about these issues and their rights under state law.

If possible, we recommend working with an independent professional, such as an attorney or geriatric care manager, to help you navigate these issues. In addition, your state agency might have helpful information about consumer rights, industry standards, and the extent to which a specific assisted living has been subject to enforcement actions. See the [Assisted Living State Requirements Chart](#) on the Assisted Living page of our website, www.nursinghome411.org, for links to your state agency's website.

We do not recommend using a private service, such as "A Place for Mom," when evaluating potential communities since these services typically receive payment from providers in order to be listed.

What is Assisted Living?

Generally speaking, assisted living residences provide a combination of housing and supportive services for individuals not requiring round-the-clock nursing care but who do require – or desire – to be in a residential setting that provides monitoring, personal assistance, and/or health services.

As noted above, assisted living has virtually no federal requirements. States have their own definitions and requirements which tend to be limited and confusing. States may use different names and have different definitions and standards, for "assisted living," "adult homes," and "board and care homes." When exploring your community's assisted living options, you may find different populations served, different accommodations on offer, different payment options, and differences in the ability to safely stay in the assisted living if your needs increase.

Services also vary, sometimes significantly. Some residences provide apartments with kitchenettes, while others offer private or shared rooms. Services may be limited to housekeeping and personal care (such as help with bathing and dressing) or include medication management, dementia care, and even medication management. Typical services include meals that are served in a common dining room, personal care, housekeeping, and activities.

EXPLORE YOUR OPTIONS

First, we encourage you to explore the whole spectrum of available options. Do you still live at home? If so, before deciding on assisted living, you may want to find out whether you can get home care, housekeeping, or other services – and what they would cost. These services could

help you stay in your own house or apartment. Many people prefer to stay at home. Your own home is familiar, and it may be where you have the most freedom to lead your life as you want.

Maybe you can still take care of yourself but want the companionship that communities offer. If so, another option to consider is independent living, also called retirement communities, congregate living, or senior apartments. Independent living typically provides seniors with recreational,

educational, and social activities. Although such residences may also provide laundry, linen, meal service, and transportation, they almost never offer any personal care or health services.

Perhaps you can't live safely at home or manage on your own as you once did. Or you may be anticipating your future needs. Assisted living is a group living arrangement that can be beneficial, especially if you feel lonely at home because of disability or the loss of your spouse, partner, or other family or friends. But assisted living does require compromises you wouldn't have to make living in your own home.

If possible, speak to family and friends about their experiences with assisted living and other long-term care services. The local Agency on Aging and the Long-Term Care Ombudsman Program, which exist in communities throughout the country, can provide information about how to find high-quality assisted living. In addition, "[No Wrong Door](https://nwd.acl.gov/index.html)" (<https://nwd.acl.gov/index.html>) tools and resources are available nationwide to help people navigate the long-term care system in their communities.

THE KEY TO CHOOSING A RESIDENCE

By assessing what you need and want, you'll know which questions to ask when visiting assisted living residences.

Basic Considerations

Many people are forced to choose assisted living residences under time constraints during a health crisis. Planning ahead can give you have sufficient time to evaluate options as an informed consumer.

Your first consideration in choosing an assisted living residence should be the services offered and whether they will meet your needs and preferences. Will you get the help you need when you need it? Does the facility offer activities you enjoy? What housekeeping services are available? Are they included in the monthly fee?

As with any living choice, location is an important consideration. You'll want to be as close as possible to your family and friends who mean the most to you. Even within the building, location is important: a single apartment located close to an elevator may be more desirable — and expensive — than a room further down the hall. A shared room will be more economical than a single room.

This brings us to cost and payment. Medicare does not cover assisted living at all. Many states now cover some services under Medicaid, though the availability of Medicaid assisted living benefits is usually limited (another reason to plan ahead!). Some, but not all, private long-term care insurance policies cover assisted living services. As a result, most people pay out of pocket. Thus, it is important to find out how monthly fees are set, and whether there are additional

costs for certain services. Generally, fees can rise at any time and extra services may increase costs. Residences may also charge an entrance fee, additional community fees, or require a security deposit.

Make Many Visits

Try to visit at least a few assisted living communities to decide which best meet your needs and desires. If possible, visit any facility under consideration at various times of day, including at least one unannounced visit on an evening or weekend. Try to visit during at least one meal so you can taste the food and see how residents are experiencing their meals.

Ask Questions

Navigating the world of assisted living is a challenge but asking the right questions – both to yourself and to your prospective facilities – can help you in finding a community that is best for you and your family. Several helpful questionnaires can be found at the end of this guide and on our website (see link above).

Questionnaire forms can be accessed and completed by hand or electronically (computer, tablet, phone). These forms provide specific questions to help you determine if a facility meets your current and future needs. Feel free to add, remove, or modify questions so that they better suit your needs.

Speak to as many people as you can who live and work at the residence. You'll probably meet first with the administrator, marketing director, or admissions coordinator. Also, make sure to speak with other staff members, including personal care aides, activity staff, and the nurse (if there is one).

Other residents and their family members can provide valuable insight. Ask them what they like and dislike about the facility. Talk with residents who are outside or in the lobby, where they may feel free to give honest answers about staff ratios and Resident Council activity.

The questionnaires in this guide are also available on our website, <https://nursinghome411.org/assisted-living-guidebooks/>.

They can be accessed and completed by hand or electronically (computer, tablet, phone).



Questionnaire: Initial Questions For Administration & Staff

See Page 11 of this guide or visit <https://nursinghome411.org/assisted-living-guidebooks/> for a list of questions you can ask staff to help determine whether a prospective residence is right for you.

YOUR CHOICES AND PREFERENCES

You probably want to retain control of your life and maintain your lifestyle even though you're not as independent as you once were. You want your individual choices honored, such as when you prefer to wake, bathe, or eat.

Some assisted living residents complain they aren't provided with real options. Instead, staff and management select limited alternatives in advance and then offer them to residents.

The management of assisted living residences often makes house rules and structured routines to balance competing demands of residents and staff. How, when, and how often things are done may result from staff levels and schedules. Specific times for bathing, meals, visiting hours, and shopping trips may limit your options and ability to make your own decisions.

Before choosing a residence, you should explore what kinds of help you need and how you prefer to lead your life. **You can use the questionnaire on page 13 to help identify and write down**

your needs and preferences. This can be very helpful when you consider and visit an assisted living residence, since it will help you organize your priorities and prepare questions to ask staff. For instance, if you need help dressing and prefer to get up at a certain hour, you'll want to know that staff can dress you when you want to get up. This information will help you decide whether a residence meets your needs and preferences—and if it's right for you.

It is important to think realistically about your needs when completing this questionnaire. If you must rely on others to help you do certain things, you may not be able to lead quite as independent a life as you once did. It's possible that you'll have to balance what you want (your preferences) with what you need.

NOTE TO FAMILY MEMBERS:

You can help your loved one identify their needs and preferences by discussing these questions with them. If your loved one has dementia, there might be certain times of day that are easier for them to talk about their preferences. Your knowledge of him or her can be helpful in filling in any gaps.



Questionnaire: Your Needs & Preferences

See Page 13 for a questionnaire to help you better understand your needs and preferences, and how they might be addressed by a prospective residence.

MAINTAINING THE ABILITY TO MAKE YOUR OWN DECISIONS

Maintaining the ability to make your own decisions may be important to you. You might value, for instance, deciding whether to go for a walk by yourself even if there is a chance you might fall. You might prefer to walk on your own even if your family or the residence staff thinks you'd be safer in a wheelchair.

You might value the ability to decide whether to take specific preventive health actions such as dieting or avoiding smoking and alcohol.

Although consumers want to make their own decisions – and assisted living promises this for their residents – the issues can sometimes be complex and difficult. Several barriers may prevent your ability to live your life the way you'd like.

Staff and Family Concerns

The staff of your residence may try to balance your right to live the way you want with their perceived responsibility for your safety and well-being. These concerns may limit your independence. For instance, you may want to go for a walk alone, knowing a fall is possible, but staff may stop you because they feel the danger of your falling is too great, or greater than you think it is. They may feel their job is to protect you rather than helping you be as independent as possible. This attitude may stem from their own beliefs, from your family's instructions, or from their perceptions of government regulations. They may also be concerned about legal liability.

Don't take for granted your rights when faced with these possible limitations. Ask questions (see examples below) and talk with your family and the staff about your priorities, the things you want to do, and the decisions you want to make for yourself.

Feeling Overwhelmed

It's easy—and natural—to feel overwhelmed when faced with selecting an assisted living residence or negotiating the world of assisted living. For some, it may seem too technical and health oriented. All your life you may have followed recommendations from a doctor or healthcare provider, and may assume that they know better and should make decisions for you.

In reality, the choices involved in assisted living have long been under your control. It's possible to respect the authority of your doctor and other health professionals – yet still decide about the other important aspects of your life. It's not just about healthcare.

HELP PLAN YOUR CARE

You probably want to maintain as much independence as possible. This may require that you receive services tailored for your individual needs. Assisted living can help you get the assistance you need so you can do more for yourself and enjoy some of your favorite activities that might not be available if living alone at home.

Assisted living facilities often have a Resident Service Plan that documents staff responsibilities and scheduling for a resident. The Resident Service Plan is based on a planning process that aims to identify your needs (i.e., communicating in a language other than English). It's important for you to see this plan—and to help develop it—to ensure it reflects your preferences.



Questionnaire: What to Look For

See Page 15 for a questionnaire to help you determine if a facility's physical layout can meet your needs.

WHAT TO READ

Take time to read and review written information on resident choice and control, and the ability to remain in the residence. Ask management for a copy of the facility's house rules, policies, financial reports, and any inspection reports. You can obtain inspection reports from the agency responsible for monitoring assisted living in your state such as the state health department. Your state may also have a Bill of Rights specifically for assisted living residents.

Most important is the contract or admissions agreement for the residence. Before signing, take it home with you at the end of your visit and examine it thoroughly in the privacy of your home. You might also want to get a lawyer's help to ensure your rights are protected in the future.

Before signing a residency agreement, it is important to understand which services are included and which services will incur additional costs. **See the questionnaire on Page 20** to help get a sense of a specific assisted living's charges.

WILL I NEED TO MOVE?

Maybe you're considering moving to assisted living because you don't want to live in a nursing home. You're carefully selecting a residence, accounting for its location, price, and ability to meet your needs and preferences. If you must move away from that setting, another place may not share these features, and you may miss the friends and staff from that previous facility. Research has shown that when older adults are moved from place to place, especially when their health is failing, they are likelier to become sicker and confused.

The questionnaire on Page 20 can help you determine when you might need to move. You should also consider the following questions:

What if I can't afford the extra services required if I become frailer?

In a residence that accepts only private paying residents, you may be able to stay there as you become more disabled only if you can afford the extra costs of your services. If you cannot, you'll likely be asked to leave the residence or transferred to a nursing home.

Will government regulations force me to leave the residence if I get too frail?

State and local government agencies that oversee assisted living may have rules that force you out of the residence if you become too sick.

Do I have any tenant rights?

When you rent or own your own apartment or house you may have certain rights established by your local or state government. Find out if these rights apply to you as an assisted living

resident or if the law in your state provides similar protections for assisted living residents. Check with your [LTC Ombudsman Program](#) or an organization in your state that advocates for seniors or long-term care consumers.

What are the residence's mission and policies?

Many managers of assisted living residences grapple with the tension that may arise when residents who are more independent don't want to live with more disabled residents because they believe it would diminish their own quality of life. Some managements are so eager to avoid "looking like a nursing home" that they won't accommodate anyone who's incontinent, confused, or in a wheelchair. You might want to ask:

- Have residents who are more dependent affected the quality of life of more independent residents?
- If so, how has the management address this situation?

Ask yourself:

Do I want to be able to stay in the residence if I become more frail?

While most people would prefer to stay where they are as their needs increase, many assisted living residences may make you leave if you become more dependent. They may not have staff that are qualified to provide higher levels of care. On the other hand an assisted living residence may retain residents that it can no longer care for safely because it does not want to lose the income from those residents.

A FEW FINAL NOTES

For many seniors, it is important to select an assisted living residence that fosters independence, choice, and autonomy. We hope that this guide and the questionnaires will help you identify what you need and prefer in respect to the services that assisted living can provide and evaluate the ability of the residences you visit to meet your needs.

If you do decide on an assisted living residence, please see our guide for residents who are living in assisted living, which is geared to helping them maintain choice and autonomy in their communities. That guide, also available at, <https://nursinghome411.org/assisted-living-guidebooks/>, provides information and tools to help residents overcome challenges they may encounter and improve their quality of life.

Questionnaire: Initial Questions For Administration & Staff

Ask the following questions to help determine whether a residence is right for you.

1. Is the facility licensed and, if so, what type of license does it have?
2. Is there an inspection report available to review?
3. How stable is the residence financially? [Ask for a copy of their annual report. Search online for any media coverage of the company.]
4. Who draws up the Resident Service Plan (an individualized list and schedule of which services each resident receives, and when they are to receive them)? How involved is the resident and family in this process?
5. If monthly fees are based on a service formula, how often is it reassessed? When fees rise, how far in advance are residents notified?
6. Who decides about transferring residents within and outside the residence?
7. Is a nursing home affiliated with or attached to the residence? [If yes, we recommend visiting the nursing home and viewing its rating on <https://www.medicare.gov/nursinghomecompare/search.html?>.]
8. How are grievances handled?
9. Is there a Resident Council? A Family Council? If so, who run the councils?
10. Is there a probationary period after a resident moves in?
11. What happens in a medical emergency?

Questionnaire: Initial Questions For Administration & Staff

12. What are the facility's training and professional requirements for staff who provide resident monitoring and services?

13. How many staff are in the facility during the day, overnight, and on weekends?

14. Do frailty or a medical condition limit your choices and activities, such as walking or eating certain food? If so, ask the staff:

14a. How do you deal with residents who have a history of falling, but who like to go for walks alone outside the building?

14b. How do you react to residents who occasionally eat foods not on their diets?

15. Is it important for you to do things that others might consider unsafe, but seem either safe or worth the risk to you? If so, ask the staff:

15a. Can I come and go as I please?

15b. Can I take a late night walk if I want?

16. Can I smoke? In my room? In special areas in the building or on the grounds?

17. Can I drink alcohol? In my room, public areas, or the dining room?

18. What if I want to do something my family deems unsafe?

Notes:

Questionnaire: Your Needs and Preferences

These questions can help you better understand your needs and preferences, and how they can be addressed by a prospective residence.

What are your needs and preferences in respect to...	Questions to Ask
Walking? Dressing? Eating? Bathing? Toileting?	Can I decide when I: <ul style="list-style-type: none"> • Get up? • Go to sleep? • Eat breakfast, lunch, and dinner? • Shower or bathe? Are there snacks available 24/7 (and what are they)?
Cooking?	If there's a kitchenette, is it open 24/7? Can residents access appliances such as a refrigerator or microwave? If no kitchenette, what opportunities are there to prepare snacks or meals?
Doing laundry?	Is there a laundry for residents' use? Can I do my own laundry?
Having visitors?	Can I have visitors at many times of day?
Reading?	Can someone from the residence read to me? Can someone read to me in my language if it isn't English? Are large-print books available? Audiobooks?
Getting places?	What transportation is available from the residence? What options are there for individuals to schedule outings other than medical appointments, residence scheduled trips, or other group trips? What public transportation is available, and is it accessible? What's within safe walking distance for me? (Shopping? Park? Library? Bank?) Do residents have a curfew?

Questionnaire: Your Needs & Preferences

	What are the procedures if I decide to stay overnight with a friend or go on trips overnight?
Maintaining involvement in your neighborhood and larger community?	What opportunities are there to continue my community activities, such as attending my place of worship, or clubs or organizations to which I belong?
Other community involvement?	What other opportunities are there to engage in community activities?
Regular supervision from a doctor or nurse because of a medical condition? Managing or taking your medications?	What opportunities are there to be involved and have a say in my medical treatment? Can I refuse medications, services or treatment?

Notes on Needs and Preferences:

Questionnaire: Will the Physical Layout Meet Your Needs?

Each of your visits should include a tour of the building, grounds, and neighborhood, and should offer sufficient opportunity to ask questions. Here's what to look for on your visits.

Note: This questionnaire contains five pages and 12 categories. Focus on the categories that matter to you.

1. Entrance

- Does it allow easy access outdoors and to the rest of the building?
- Can I enter from the street without using steps?
- Is there room for wheelchairs and walkers?
- Are residents engaged in socializing or participating in activities in the lobby and other public areas? Or do too many seem stuck in their rooms?

Notes _____

2. Individual Units

- Is there variation in the design and decoration of the resident units?
- How much of my own furniture and furnishings can I bring?
- Can I arrange furniture as I like?
- Do I have a key to my unit? Can I lock the door from the inside?
- Who else would have access to my unit?
- Do I have individual temperature control?
- Can I have overnight guests without checking with management?
- What storage space is available?

Notes _____

Questionnaire: Will the Physical Layout Meet Your Needs?

3. Kitchen

- If there is a kitchen or kitchenette, can I reach the cupboards?
- What appliances are provided?
- What appliances may I have in my room (e.g., a small refrigerator, microwave, coffee maker, tea kettle)?
- If there's no kitchen, what opportunities are there to prepare my own meals?

Notes _____

4. Bathroom

- Are bathrooms shared or private?
- Are there safety railings in the bathroom and a seat in the shower or tub?
- Are there call bells in the unit? In the bathroom?

Notes _____

5. Dining Room

- What food choices do I have?
- Can I choose when to take my breakfast, lunch, and dinner?
- What if I'm hungry at 2 a.m.?
- How is dining room seating arranged, and what are my options?
- Can I eat alone?
- Can I eat in my room?

Notes _____

6. Common Areas

- Where are the common areas for residents?
- What activities do they provide for residents (e.g., social lounges, quiet sitting areas, a library, a games or hobbies room)?

Notes _____

7. Hallways

- Are there handrails?
- Is the lighting adequate?
- Are the floors non-skid?
- Is it easy to find my way around the building?

Notes _____

8. Lighting, Layout, and Physical Condition

- Is the lighting bright?
- Do I like the layout?
- Does the building seem in good shape?

Notes _____

9. Outside Areas

- Are there communal areas including covered porches protected from the weather?
- Are they safe (enclosed, visible from facility, with call bells)?
- Are there sidewalks, paths, and walkways accessible to people in wheelchairs or using canes and walkers?
- Are there benches and chairs for resting?

Questionnaire: Will the Physical Layout Meet Your Needs?

- Are tables available?

Notes _____

10. Staff

- Do staff members refer to residents by name?
- Do they treat residents with dignity and respect?
- Do they seem to care about the residents? Do they ignore residents or seem patronizing?
- Is my tour guide asking me about my own needs?
- For how many hours are staff trained in first aid, CPR, emotional needs, and residents' rights?
- If I speak a language other than English, is there staff available to understand me and communicate my needs and preferences to others?
- Is a nurse on staff?
- Do doctors visit periodically?
- Can I continue to use my current doctor?

Notes _____

11. Pets

- Is there a chance to keep my pet, which may help me feel much happier?
- If I'm allergic to pets or don't like them, is there a way for me to avoid them?

Notes _____

12. Neighborhood

- Is the residence integrated into the neighborhood or surrounding area?
- Is it in easy walking distance to local shops, a grocery, pharmacy, library, bank, post office, movie theater, park, church, mosque, or synagogue?
- Is public transportation or para-transit available?
- Is there enough outdoor space?
- Are the sidewalks flat?

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Questionnaire: Questions & Considerations Before Signing a Residency Agreement

It is important to understand what services are included in the basic monthly fee and what services will incur additional costs. Use the following list of common services and fees to get a sense of a specific assisted living's charges and to compare charges and policies between different communities under consideration.

Service	Included?	Notes
Room		
Meals		
Snacks		
Housekeeping		
Activities in the assisted living		
Activities in the outside community		
Personal care services		
Bathing assistance		
Medication assistance		
Additional fees or recurring charges (such as an entrance fee or community fee)		

Questions For Staff: When Might I Need to Move?

Can you care for me here if I become frailer? An assisted living residence may lack the staffing or expertise to care for you if you become sicker and more disabled. Ask:

1. How much staff is there? What are their qualifications? Is there an RN on staff and how frequently are they at the facility?
2. What is the facility's policy in respect to residents with Alzheimer's Disease or other cognitive impairment (including early stage and later stages)?
3. What disabilities would cause me to move?
4. What trainings are required for staff? (e.g., elder care, dementia care, medication management). How frequently do they receive training?
5. Are therapeutic programs and assistive devices available?
6. Can you adapt my apartment or room if I become more dependent?
7. What happens if I become incontinent (or need a wheelchair, oxygen, I.V.)?
8. Will I have to move my room or apartment if I become more dependent?

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LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

The Long Term Care Community Coalition (LTCCC) is a non-profit organization dedicated to improving care and quality of life for residents in nursing homes and assisted living.

For free resources, including factsheets on standards of care, forms for tracking and filing a complaint, and information on nursing home staffing and other quality indicators, please visit our website:

www.nursinghome411.org

Sign-up for alerts: <https://nursinghome411.org/join/> or call 212-385-0355 or email info@LTCCC.org.

Follow us on Twitter: twitter.com/LTCconsumer

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If you would like to support our mission, please visit <https://nursinghome411.org/about-ltccc/> or send a check to LTCCC, One Penn Plaza, Suite 6252, New York, NY 10119.