

Maintaining Independence & Choice in Assisted Living: *A Guide for Residents*



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Note to Family

This guide promotes older adults' rights to make decisions about their own lives in assisted living. That's why it speaks directly to seniors. But it can also be helpful to you. The ideas here can help you as you help them get needed services while helping to maintain their independence, choice, and decision-making.

Say your mother is having some cognitive issues. Maybe she cannot live safely on her own. But she probably still has strong feelings about what she likes and dislikes—clothes to wear, food to eat, whether she takes a bath or shower. Even if you are most concerned about her safety, she should get to choose what matters to her. Research shows that when elderly individuals lose their independence and feeling of control, they get sicker. This guide will help you as you work with your mother to identify what she needs and wants to keep living as independently as she can.

The staff may see you, not your relative, as their customer. You can help them to focus on your relative and their needs and preferences. For instance, if staff ask you about what your relative prefers, we recommend re-directing the staff to ask your relative and get to know him or her. The focus should be on what he or she wants, rather than what you want. And it is critical that the facility's staff and services are meeting each resident where they exist, based upon their abilities, cognitive status, etc....

The Promise of Assisted Living

Assisted living offers the promise of safety and monitoring in a setting that fosters resident independence and choice, with services tailored to meet individual needs and preferences. But achieving this promise is hard. You can help yourself, other residents, and the staff and management to do better.

This Guide's Purpose

If you (or a loved one) are living in an assisted living residence, this guide is for you. It should help you get what many seniors want from assisted living:

- To control your life and be as independent as possible.
- To stay in the residence, if you want, as you become more dependent.

More Choices and Independence

This guide helps assisted living residents check how much their assisted living community supports their choices and independence. It suggests ways to work with staff and other residents to improve things if needed.

How to Use This Guide

You will find a series of questions to ask yourself to check how well your residence is meeting your needs and preferences. First, answer these questions. If you wish, you can ask a family member or friend to help you.

Second, if you find that your residence could meet your needs and preferences better, you will find ideas for things you can do by yourself and with other residents to improve the situation.

You can discuss your concerns—and work to solve them—with other residents, the management and staff, and your **Resident Council** (if you have one). [See “What You Can Do with Other Residents” on Page 8.]

The following sections discuss things to think about and ask yourself to help you maintain choice and independence in ways that are important to you.

Don't have a resident council? Consider forming one.

Other residents may share your concerns. By talking with them, you can help improve your residence for everyone. [See “How to Make Changes,” starting on Page 7, for ideas on what you can do—on your own and with other residents.]



Note: This guide contains questionnaires to help you assess your assisted living residence. These forms can be completed by hand by printing out the pages you need. They can also be downloaded from our website, <https://nursinghome411.org/assisted-living-guidebooks/>, and completed electronically on your computer, tablet, or smartphone.

Keeping Your Independence

You either can't live at home anymore or have chosen not to. Likely, you couldn't manage on your own at home as you once did. Maybe it was hard to climb in and out of the bathtub, get dressed, or leave the house to take a walk.

Assisted living should give you the help you need, so you can do more for yourself and enjoy more of your favorite activities and interests than you could at home.



The questionnaire on Page 10, “Does Your Residence Meet Your Needs,” provides a set of questions to help you evaluate how staff is serving you.

Your Resident Service Plan

You can control your care: The services you receive, how often you receive them, who provides them, and how. Many assisted living residences have a plan indicating what staff will do for each resident and when help will be provided. This Resident Service Plan comes from a process that aims to list all your needs for help. It's important that you see this plan and help develop and update it. Involving yourself in the process can help ensure that it reflects your current needs and wants. [See "Take Part in Your Resident Service Plan" on Page 7.]

Having Choices

Everyone wants their individual choices honored, especially when it comes to personal lifestyle matters, such as when to wake up, bathe, and eat. How we spend our time – and with whom – are also important.

Some assisted living residents complain they can't achieve control, and that staff and management don't give them options, instead selecting limited alternatives in advance.

Assisted living residences face competing demands, as group living settings (for residents) and workplaces (for staff). Staff levels and schedules may shape how, when, and how often things are done by the management's house rules and structured routines. Set times for bathing, meals, visits, and shopping trips may limit your options.



See the questionnaire on Page 11, "Can You Choose What You Want at Your Residence," to assess whether your choices are being honored.

It's not just about healthcare

Dealing with the world of assisted living may seem too medical. You may feel your doctor or nurse knows best.

But all your life you've been controlling many of the choices involved in assisted living, such as setting your own daily schedule or food to eat.

Making Your Own Decisions

You want to keep your power to make decisions about the parts of your life that matter most to you, even if staff or family thinks that you should do otherwise. For example, you might like to smoke, drink alcohol, or go off a special diet on occasion. Even if these activities risk harming your health, you may want to do them anyway. At the same time, staff and family concerns may limit you from living your life the way you'd like.

Staff and Family Concerns

The staff of your residence—and your family—may try to balance your right to live how you want with the way they see their responsibility for your safety and well-being.

- Maybe it's important for you to decide whether to go for a walk by yourself, as best you can, knowing you might fall. But the staff may think you'd be safer in a wheelchair. They may feel your danger of falling is bigger than you think.

The staff may feel their job is to protect you and do things for you, instead of helping you to be as independent as possible. This may come from their own beliefs, from your family's instructions, or from what they think a government agency requires. They may also be concerned about getting sued.

But you don't necessarily have to accept these limits. See "How to Make Changes" (page 7) for suggestions on overcoming limits to your independence and choices if this is a problem for you. Speak with your family and the staff about what you want to do and which decisions you want to make for yourself.



See the questionnaire on Page 14, "Can You Decide for Yourself at Your Residence," to assess whether management and staff are letting you make your own decisions.

Staying in a Residence

One big decision you may wish to make for yourself is to stay in your residence if your needs increase or you become frailer. When older people move, especially if their health is fading, they're more likely to become sicker and confused.

Maybe you chose assisted living because you didn't want to live in a nursing home. You carefully selected your residence. If you have to move away, another place may have a worse location and price—and may not meet your needs and wishes as well. And you'd miss the friends you've made and the staff you know.



See the questionnaire on Page 16, "Can You Stay if You Become More Dependent?," to assess whether management and staff will support your ability to stay in your residence.

How to Make Changes

You've checked out your community, but maybe you've found limits to your independence, choices, and decision-making—or your ability to stay if you become frailer—that you would like to change. This section discusses how you can address these challenges and help achieve assisted living's promise:

What You Can Do by Yourself

Make Informed Decisions

Understand the benefits, risks, and possible effects of any decision you make. Seek the information you need and talk to people you trust. When you make informed decisions, others are likely to respect your decision. For example, what might happen if you sometimes eat food that isn't on your special diet?

Tell Your Family and the Staff What Matters to You

Both your family and facility staff generally mean well and are concerned about your safety and well-being. Tell them about your priorities and values. Explain the benefits of any choice you want to make—even the plus side of any risks you may want to take.

- Want to take a walk by yourself? Tell the staff if you've always loved walking. Explain that it may help keep up your strength.

Take Part in Your Resident Service Plan

If you want your services provided in a certain way, you need to make sure your **Resident Service Plan** reflects your needs and preferences. Find out if—and when—staff members meet to discuss your plan. Your doctor or nurse should be available to discuss your medical needs and how to meet them. Attend these meetings (with your family if you prefer). Help write and update your plan to ensure it reflects your needs and preferences. For example:

- Do you like baths, not showers?
- Are you trying to be more independent in toileting yourself?
- Do you need to share your needs in a language other than English?

Your plan should say so.

Go to the Administrator

The administrator leads the staff and sets the community's operating standards, including the residents' levels of independence and choice. Good administrators keep their doors open to residents, listen to their individual concerns, and welcome ideas and suggestions. Get to know your residence's administrator and let them know you.

Know Your Rights

Rights seldom come automatically. You must assert them. The first step? Find out what they are by reviewing:

- Your rights as an assisted living resident in your state. If your assisted living does not post this, information on these rights can often be found online or by contacting your LTC Ombudsman Program (see https://theconsumervoice.org/get_help).
- Your admissions agreement or contract.

Remember: Just because you are in an assisted living community does not mean you have forfeited your rights as a resident or citizen of the United States!

Know How to State Your Grievances

Every assisted living should have a way for residents to voice a grievance, and it should respond quickly and seriously to input it receives. Ask how to report a complaint or grievance in the residence, and don't be afraid to do it if need be. Some residents may not raise real grievances, because they fear going against the residence. But resident grievances are an important way to ensure good care and quality of life for everyone.

Find and Use an Advocate

Sometimes you may want an outside advocate's help—maybe to get information, or to help resolve a complaint that wasn't handled well. Know the advocacy resources in your community and call on them when needed. Every assisted living resident has the right to access the services of the **Long-Term Care Ombudsman Program** (see <https://ltcombudsman.org/assisted-living> for more information on the Program and how to access services from your local office). Your local **Agency on Aging** may list other advocacy groups in your area. These organizations may be part of a big consumer community, where you can join with others to achieve the potential of assisted living.

What You Can Do with Other Residents

Consider Being Active in the Resident Council

A resident council is an organization of residents like a tenants' association. It gives you a say in how your residence is run. If your community has one, consider taking part.

The Council can give residents a common purpose. You're all individuals, but you make up a community. It can help develop varied educational programs and activities that promote mutual support:

- Welcoming committees for newcomers.
- Showcasing residents' talents, opinions, and volunteer efforts in the larger community.
- Raising funds to support special programs.

Living with so many people, you each may have to make some compromises and limit your options. Each resident can't make a completely different choice about everything. But the council can help address disagreements by providing a forum to discuss and resolve them. Together, you can agree on what will suit most of you fairly.

The Council can also extend your power and participation in the community. If you have a complaint about your choices, needs, or preferences, other residents may share it. You can work together to resolve it or voice your concerns with the administration in an organized way. Groups of people often have more power and say than individuals. Administration might be more willing to listen to multiple residents with the same issue than to only one person.

- Let's say you and other residents think set schedules and options limit your choices too much. It could be mealtimes, menu choices, activities, or the van schedule. The council could see how well these routines and choices serve the residents, talk about how to improve them, and work with staff to change them.
- Maybe you and other residents feel the staff doesn't encourage independence. The Council could suggest helping to train the staff or adding new programs. Your assisted living's management can benefit from residents' feedback, since it can help them to have a community that better meets the needs and preferences of its customers: you and the other residents.

If There's No Council, Consider Forming One

Start forming a resident council by meeting with other interested residents. Explore ideas and get the administration's support. Sound people out one by one. Reach out to existing resident groups or clubs, if there are any.

To present the idea of a council to the whole community, your small group can plan an event. It could include a talk by your residence's administrator or someone from the local LTC Ombudsman Program. The group could vote on forming a council or choose a steering committee to begin initial planning to establish a council.

Councils can be set up in any way that residents prefer, based upon their goals and interests. Some councils have informal town meeting for residents while others have a formal structure, with officers and floor representatives. Members can decide whether to use a staff facilitator, set bylaws, etc.... Council programs could grow out of existing resident groups or by surveying residents' common needs and special interests.

QUESTIONNAIRES

Does Your Residence Meet Your Needs?

In dressing, bathing, walking, cooking, and cleaning, the staff should encourage you to do as much for yourself as you can. Use this questionnaire to evaluate how they're serving you. The more "Yes" replies and less "No" replies, the better.

	Yes	No	N/A
If you need it, does the staff set out the clothes you want to wear so you can dress yourself?			
If you need a health or wellness program, or assisted devices like special forks or spoons to eat, are they supplied?			
If you have problems walking, does the staff give you enough time to get to the dining room and activities? If they walk with you, do they follow your pace?			
If you need help moving around, has the management added bathtub grab bars or kitchen cabinets that you can reach?			
If you want to take walks outside, are the sidewalks flat and even, and are your favorite places nearby?			
Has the management found an option for you to come and go safely?			
Is a van available, or a staff member assigned (with your permission) to go with you?			
Does the building have handrails in the hallways and resting areas every few feet if you need to stop?			
Is the dining room close enough to your room or apartment for you to walk there?			
When you'd rather be alone, can you avoid group activities?			
Does the staff always knock before coming into your room or apartment?			
Can your family visit whenever you want them to? May you give them a copy of your key?			
Can you come and go as you please?			
Notes:			

Can You Choose What You Want at Your Residence?

The management and staff should grant your choices as much as possible. For each question that applies, check “Yes” or “No.”

	Yes	No	N/A
Is it important for you to set your routines, such as deciding when to get up, go to sleep, eat meals, or bathe/shower? Check “Yes” if any apply.			
Can you decide when to get up, go to sleep, eat meals, or shower/bathe? If not, note specific concerns here:			
If you need help bathing, dressing, getting up, or going to sleep, is staff available to help you? If not, note specific concerns here:			
Is it important for you to cook?			
<ul style="list-style-type: none"> If you have a kitchenette, are appliances accessible? 			
<ul style="list-style-type: none"> Can you reach the cupboards and use the faucets? 			
<ul style="list-style-type: none"> If you don’t have your own kitchenette, can you ever prepare your own meals? 			
Is it important for you to do your own laundry?			
<ul style="list-style-type: none"> Is there a laundry for resident use? 			
Is it important for you to keep house?			
<ul style="list-style-type: none"> Can you get help doing your own laundry or housekeeping if you need it? 			

Questionnaire: Can You Choose What You Want at Your Residence?

Is it important for you to invite over friends and relatives?			
<ul style="list-style-type: none"> • Can you invite over friends and relative? 			
Is it important for you to manage your money?			
<ul style="list-style-type: none"> • If you need help paying bills, does the residence provide it? 			
Is it important for you to read?			
<ul style="list-style-type: none"> • Are large-print books available? 			
<ul style="list-style-type: none"> • Is there internet in the building? 			
<ul style="list-style-type: none"> • Are computers or iPads (or tablets) available? 			
<ul style="list-style-type: none"> • Are residence newsletters and house rules in large print? 			
<ul style="list-style-type: none"> • If you need help reading, can someone from the residence read to you? 			
<ul style="list-style-type: none"> • Can someone read to you in your language if it isn't English? 			
Is it important for you to take part in activities you've always enjoyed?			
<ul style="list-style-type: none"> • Does the residence have these activities available? 			
<ul style="list-style-type: none"> • Does the residence have activities that you like? 			
Is it important for you to go to certain places such as a supermarket, department store, a friend or family's place, park, library, museum, bank, etc.?			
<ul style="list-style-type: none"> • If these places aren't close, has staff helped you get there? 			
<ul style="list-style-type: none"> • Is transportation (public or private) available and accessible? 			
<ul style="list-style-type: none"> • Are there options for you to schedule outings other than to medical appointments, residence-scheduled trips, or other group trips? 			
<ul style="list-style-type: none"> • Can you decide to stay overnight with a friend or go on trips overnight? 			

Questionnaire: Can You Choose What You Want at Your Residence?

Is it important for you to maintain involvement in your neighborhood and larger community (e.g. religious groups, clubs)?			
• Do community groups meet in your residence?			
• Can you keep up your community activities?			
• Do community groups meet in your residence?			
• Can you go to your place of worship, club, or organization you belong to?			
• Are there other opportunities to take part in community activities?			
Notes:			

Can You Decide for Yourself at Your Residence?

These questions will help you check how much the management and staff let you make your own decisions. Some questions have space for you to write responses.

	Yes	No	N/A
Is it important for you to make decisions about your medical care?			
<ul style="list-style-type: none"> If you've ever refused a medication or treatment, what happened? 			
<ul style="list-style-type: none"> Have the management and staff, after discussing it with you, your family, and your doctor, explained the likely outcome of your refusal? 			
<ul style="list-style-type: none"> Have they respected your wishes? 			
<ul style="list-style-type: none"> If you want, can you seek out and use alternative forms of medical care or treatment? 			
Is it important for you to do things others say are unsafe but you either consider safe or want to do anyway?			
<ul style="list-style-type: none"> How does the staff react if you want to do something your family feels is unsafe? 			
<ul style="list-style-type: none"> How does the staff deal with you if you like to go for walks alone outside but have trouble walking? 			
<ul style="list-style-type: none"> How does the staff react if you eat foods not on your diet from time to time? 			
<ul style="list-style-type: none"> Can you take a late-night walk if you want? 			
<ul style="list-style-type: none"> If you want to do something the staff considers unsafe or risky, have they found ways to make what you want to do safer? 			
<ul style="list-style-type: none"> Have they discussed alternatives? 			

Questionnaire: Can You Decide for Yourself at Your Residence?

<ul style="list-style-type: none"> Have they explained what they think will happen if you do what you want? 			
<ul style="list-style-type: none"> If, after all this, you still want to do something they consider unsafe, do they let you do it? 			
<ul style="list-style-type: none"> If management believes government rules limit your ability to do things it considers unsafe for you, does it share the exact wording of the rule with you and explain why? (They might be reading more into the rules than is really written.) 			
<ul style="list-style-type: none"> If you are a smoker, are there areas in the building or on the grounds where you can smoke? 			
<ul style="list-style-type: none"> If you like to have alcoholic drinks, are they allowed 			
<ul style="list-style-type: none"> Can you drink in your room or apartment, common areas, or the dining room? 			
Notes:			

Can You Stay if You Become More Dependent?

Use these questions to assess whether the management will let you stay in your residence.

	Yes	No	N/A
Is it important for you stay in your residence no matter how dependent you get?			
<ul style="list-style-type: none"> Can you stay in the residence if you become more dependent? 			
<ul style="list-style-type: none"> What if you become incontinent or need a wheelchair, oxygen, or I.V.? Would you be able to stay? 			
<ul style="list-style-type: none"> When would you have to leave? 			
<ul style="list-style-type: none"> If you can stay in the residence even if you become frailer, will you be able to stay in your room or apartment? 			
<ul style="list-style-type: none"> Will the management consider new ways to let you stay? For example, if you needed help moving from your bed to a chair and you needed to be lifted, could you lease a Hoyer lift, which the staff would need training to use? 			
<ul style="list-style-type: none"> Can they adapt your apartment or room for you if you become frailer? 			
<ul style="list-style-type: none"> If you can stay even if you become more dependent, does the residence have staff trained to care for you? 			
<ul style="list-style-type: none"> Can you offer to pay for extra help if they lack the staff to care for you? 			
<ul style="list-style-type: none"> Does it have programs to reduce falling and incontinence? 			
<ul style="list-style-type: none"> What would happen if you spent all your money and had none left? 			
<ul style="list-style-type: none"> ○ Would the residence let you stay? 			
<ul style="list-style-type: none"> ○ If not, where would you go? 			

Questionnaire: Can You Stay if You Become More Dependent?

- If you can't stay, why? (Check all that apply).

State and local government agencies that oversee assisted living have rules that would make you leave your residence if you got too sick.

Staff and management are concerned about not being able to care for you.

Staff and management worry about the possible problems of mixing independent residents with those who are more dependent.

Other. Explain:

- How do you feel about living with residents who are more dependent than you?

Notes:

Notes

Notes

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:

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