

RESIDENT'S GUIDE *for* ASSISTED LIVING



**MAINTAIN YOUR INDEPENDENCE,
CHOICE, & CONTROL**

Coalition of Institutionalized Aged and Disabled (CIAD)
The Long Term Care Community Coalition (LTCCC - formerly the Nursing Home Community Coalition)
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A VISION

The vision of assisted living is for people to control their lives as much as possible—and to stay where they are, even after they need more care.

But it's hard to make this vision real. That's what we found from studying assisted living in New York State for three years. So we're working with assisted living staff to get closer to this goal. We've written four guides:

1. **This one** helps **people now in assisted living** check how much their residence meets this potential. We suggest ways to work with staff and other residents to make it better.
2. Another helps **prospective residents** choose an assisted living community with real resident choice and decision-making power.
3. Another, for **assisted living managers**, suggests ways to overcome the obstacles that might block this goal.
4. Another helps **assisted living staff** to make this vision a reality in the residents' everyday lives.

All these guides aim to spur consumers and providers to talk together about how to make the most of choice and independence. We also hope they'll take action to help residents to stay where they are as they become more dependent. This is a vision for the future—a work in progress.

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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 help you. You may become your relative's decision-maker or official guardian. 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's having some trouble thinking. Maybe she can't decide whether to get cataract surgery. But she probably still has strong likes and dislikes—clothes to wear, food to eat. Even if you worry most about her safety, she should get to choose what matters to her. Talk with your relative about what she needs and wants to keep living as independently as she can. Research shows that when the elderly lose their independence and feeling of control, they get sicker.

The staff may see you as their customer. Help them focus more on Mom—and what she needs and wants. Visit often, and help the staff get to know her. Urge them to ask your mom what she wants rather than what you want. If she is unable to, you can tell them which choices and hobbies enrich her life most.

Ask what would happen if she ever wanted to do something they considered unsafe. Suggest that they discuss the risks and alternatives with her. Let them know that it is important to you that your mother be the one to make decisions if she is able to. Help them find ways to limit her risk if she wants to take a risk. Then she can keep the power to make decisions about the parts of her life that matter most to her.



THE PROMISE OF ASSISTED LIVING

Assisted living has the promise to help residents make decisions about their lives, while tailoring services to meet their individual needs and wants. 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's 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, even if 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 wants. 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 wants better, you will find ideas for things you can do by yourself and with other residents to improve things. Share these ideas with your family and residence management and staff.

You can discuss your concern—and try to solve it—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 19.)

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 17, for ideas on what you can do—on your own and with other residents.)

Here are things to think about and ask yourself about keeping your independence, having choices, making your own decisions, and staying in your residence:



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 pastimes than you could at home alone.

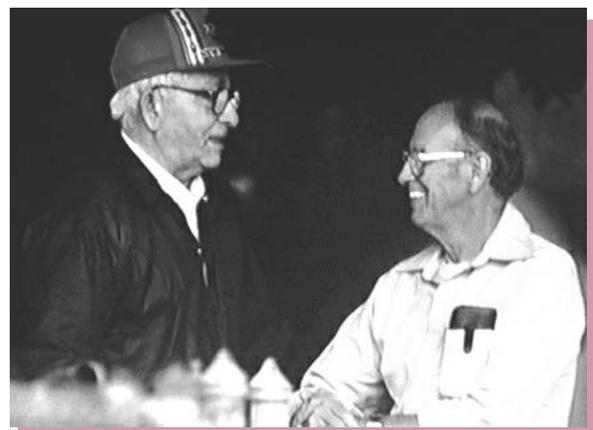
Does Your Residence Meet Your Needs?

In dressing, bathing, walking, cooking, and cleaning, the staff should encourage you to do as much for yourself as you can. Use these questions to check how well they're serving you. No place is perfect. But the more “Yes” replies, and the less “No,” the better:

- If you need it, does the staff set out the clothes you want to wear so you can dress yourself?
 Yes No

- If you need a health or wellness program, or assisted devices like special forks or spoons to eat, are they supplied?
 Yes No

- 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?
 - Yes No
- If you need help moving around, has the management added bathtub grab bars or kitchen cabinets that you can reach?
 - Yes No
- If you want to stroll in the neighborhood, are the sidewalks flat and even, and are your favorite places nearby?
 - Yes No
- Has the management found a way for you to come and go safely? Is a van available, or a staff member assigned (with your permission) to go with you?
 - Yes No
- Does the building have handrails in the hallways and resting areas every few feet if you need to stop?
 - Yes No
- Is the dining room close enough to your room or apartment for you to walk there?
 - Yes No
- When you'd rather be alone, can you avoid group activities?
 - Yes No
- Does the staff always knock before coming into your room or apartment?
 - Yes No
- Can your family visit whenever you want them to? May you give them a copy of your key?
 - Yes No



- Can you come and go as you please?

Yes No

Your Resident Service Plan

You can control your care: how many services you receive, how often, who provides them, and how. Many assisted living residences have a plan that says what the staff will do for each resident and sets a schedule to give this help. This Resident Service Plan comes from a process that tries to list all your needs for help. It's important for you to see this plan—and help write and update it. That's how you can ensure that it reflects your current needs and wants. (See “Take Part in Your Resident Service Plan” on page 17.)



HAVING CHOICES

You want your individual choices honored: when you like to wake, bathe, and eat—and how to spend your time.

Some assisted living residents complain they can't achieve real control. The staff and management don't give them real options, instead just selecting alternatives for them 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.

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.” Some have a space to write answers.

- Is it important for you to set your routines, such as deciding when to:
 - Get up? Go to sleep? Eat meals? Bathe or shower?

- Can you decide when to:
 - Get up? Go to sleep? Eat breakfast, lunch, or dinner?
 - Shower or bathe?
- If you need help bathing, dressing, getting up, or going to sleep, is staff available to help when you want to do these things?

Yes No

- Is it important for you to cook?

Yes No

If you have a kitchenette, is it wheelchair accessible?

Yes No

Can you reach the cupboards and use the faucets?

Yes No

If you don't have your own kitchenette, can you ever prepare your own meals?

Yes No

- Is it important for you to do laundry?

Yes No

Is there a laundry for residents' use?

Yes No

- Is it important for you to keep house?

Yes No

Can you get help doing your own laundry or housekeeping if you need it?

Yes No

- Is it important for you to invite friends and relatives over?

Yes No

- Can you invite friends and relatives over?

Yes No



- Is it important for you to manage your money?

Yes No

If you need help paying bills, does the residence provide it?

Yes No

- Is it important for you to read?

Yes No

Are large-print books available?

Yes No

Are the residence's newsletter and house rules in large print?

Yes No

If you need help reading, can someone from the residence read to you?

Yes No

Can someone read to you in your language if it isn't English?

Yes No

- Is it important for you to answer letters?

Yes No

If you need help writing social and business letters, is someone from the residence available to help you?

Yes No

- Is it important for you to take part in activities you've always enjoyed?

Yes No

Does the residence have activities that you like?

Yes No

- Is it important for you to go certain places, such as to:

A supermarket? A department store? Visit family and friends?

A park? A library? A museum? Your bank? Take trips?

If they aren't close, has the staff helped you get there?

Yes No

Is transportation (public or private) available and accessible to take you there?

Yes No

Are there options for you to schedule outings other than to medical appointments, residence-scheduled trips, or other group trips?

Yes No

Can you decide to stay overnight with a friend or go on trips overnight?

Yes No

- Is it important for you to maintain your involvement in your neighborhood and larger community, such as:

Your church, synagogue, or mosque?

Clubs and organizations you belong to or volunteer for?

Do community groups meet in your residence?

Yes No

Can you keep up your community activities?

Yes No

Can you go to your place of worship, or to the activities of clubs or organizations you belong to?

Yes No

What other chances are there to take part in community activities?

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. You can keep respecting your doctor's authority—yet still decide about the other important parts of your life.



MAKING YOUR OWN DECISIONS

You want to keep your power to make decisions about the parts of your life that matter most to you:

- Now and then, you might like to smoke a cigarette, drink an alcoholic beverage, or go off a special diet. Even if it risks harming your health, you may want to do it anyway.

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 need to accept these limits. See "How to Make Changes" (page 17) for suggestions on overcoming limits to your independence and choices if this is a problem for you. Talk with your family and the staff about what you want to do and which decisions you want to make for yourself.

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 a space for you to write your answers.

- Is it important for you to make decisions about your medical care?
 Yes No

If you've ever refused a medication or treatment, what happened?

Have the management and staff, after discussing it with you, your family, and your doctor, explained the likely outcome of your refusal?

Yes No

Have they respected your wishes?

Yes No

If you want, can you seek out and use alternative forms of medical care or treatment?

Yes No

- Is it important for you to do things others say are unsafe but you either consider safe or want to do anyway?

Yes No

How does the staff react if you want to do something your family feels is unsafe?

How does the staff deal with you if you like to go for walks alone outside but have trouble walking?

How does the staff react if you eat foods not on your diet from time to time?

Can you take a late-night walk if you want?

Yes No

If you want to do something the staff considers unsafe or risky, have they found ways to make what you want to do safer?

Yes No

Have they discussed alternatives?

Yes No



Have they explained what they think will happen if you do what you want?

Yes No

If, after all this, you still want to do something they consider unsafe, do they let you do it?

Yes No

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.)

Yes No

Can you smoke in your room or apartment?

Yes No

Are there special areas in the building or on the grounds where you can smoke?

Yes No

Are alcoholic drinks allowed?

Yes No

Can you drink in your room or apartment, common areas, or the dining room?

Yes No



STAYING IN A RESIDENCE

One big decision you may wish to make for yourself is to stay in your residence no matter how frail you might become. 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.

Can You Stay if You Become More Dependent?

Use these questions to check whether the management will let you stay in your residence:

- Is it important for you stay in your residence no matter how dependent you get?

Yes No

Can you stay in the residence if you become more dependent?

Yes No

What if you become incontinent or need a wheelchair, oxygen, or I.V.?
Would you be able to stay?

Yes No

When would you have to leave?

If you can stay in the residence even if you become frailer, will you be able to stay in your room or apartment?

Yes No

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 hoier lift, which the staff would need training to use?

Yes No

Can they adapt your apartment or room for you if you become frailer?

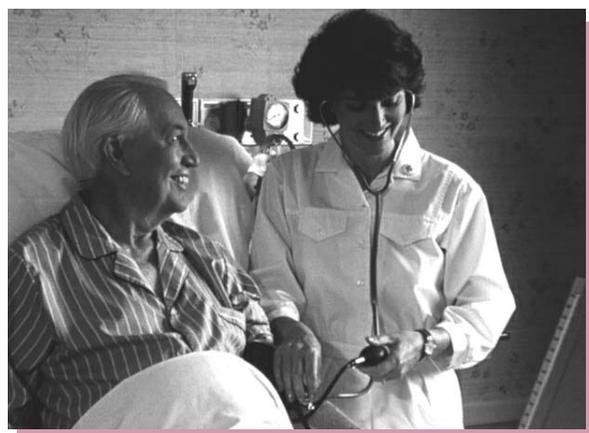
Yes No

Can you offer to pay for extra help if they lack the staff to care for you?

Yes No

If you can stay even if you become more dependent, does the residence have staff trained to care for you?

Yes No



Does it have programs to reduce falling and incontinence?

Yes No

What would happen if you spent all your money and had none left?

Would the residence let you stay? Yes No

If not, where would you go? _____

If you can't stay, why?

- The state and local government agencies that oversee assisted living have rules that would make you leave your residence if you got too sick.
- The staff and management are concerned about not being able to care for you.
- They 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 are?



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 there if you become frailer that you would like to change. Here's how you can push these limits 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

People who mean well and are concerned about your safety and well-being surround you. Tell them about your 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** describes how. Your doctor or nurse should be available to discuss your medical needs and how to meet them. Find out if—and when—staff members meet to discuss your plan. Attend these meetings, with your family. Help write and update your plan to ensure it reflects your needs and wants. 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 and wants in a language other than English?

Your plan should say so.

Just Do It

Sometimes, you just need to do something that is not ordinarily done at your residence or you are afraid to do. Push the limits on choice, control, and independence by just doing it. For example, you might:

- List yourself in the phone book
- Go out to a church, mosque, or synagogue in the community
- Order takeout food
- Rent your own videos

You took these small acts of control for granted before you moved, but in assisted living, they could be liberating for you—and other residents too. Promote individuality among other residents by your small acts of independence and by supporting their free actions.

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 their ideas and suggestions. Get to know your residence's administrator and let him know you.

Know Your Rights

Rights seldom come automatically. You have to assert them. The first step? Find out:

- Your residence's obligations to you
- Your specific rights to choice and decision-making, or general rights that support free action



- Your admissions agreement or contract or your state or local government regulations

Know How to State Your Grievances

Ask how to report a complaint or grievance in the residence. And don't be afraid to do it if need be. Every assisted living community should have a way for residents to voice a grievance, and it should respond quickly and seriously. 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 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. Many communities have a **Long-Term Care Ombudsman Program**. It can suggest ways to get the best possible assisted living. 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 letting you discuss them. Together, you can agree on what will suit most of you fairly. For example:

- Maybe some more independent residents worry about how the more disabled residents are affecting their lives. Talk it out.

The Council can also extend your power and participation by airing complaints. If you have a complaint about your choices or needs, other residents may share it. You can work together to resolve it. Groups of people often have more power and say than individuals. Administration might be more willing to listen to a number of residents with the same issue than to only one person.

- Let's say you and other residents think set schedules and options limit your choice too much. It could be meal times, 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 add new programs. The management can benefit by residents' feedback on meeting their needs and wants.

If There's No Council, Consider Forming One

Start forming a Resident Council by meeting with other interested residents and staff members. Explore ideas and get the administration's support. Sound people out one by one. Reach out to existing resident groups.

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 the president of a nearby Resident Council. The group could vote on forming a Council or choose a steering committee to define its structure or plan an election.

The Council could be an informal Town Meeting or have a formal structure, with officers and floor representatives. Decide whether to use a staff facilitator and set bylaws. Council programs could grow out of existing resident groups or surveying residents' common needs and special interests (from "Five Steps to Council Organizing," ElderCare Rights Alliance, MN, www.eldercarerights.org).



Do Your Part

The vision of assisted living is worth fulfilling. You can help make sure it is. Be an involved and informed consumer, and join with the residents and staff to meet your shared goals. Keep living as independently as possible.

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