

A GUIDEBOOK FOR FINDING  
CHOICE & INDEPENDENCE

# THINKING *of* MOVING *to an* ASSISTED LIVING RESIDENCE?



FOSTERING  
AUTONOMY & INDEPENDENCE

Coalition of Institutionalized Aged and Disabled (CIAD)  
Nursing Home Community Coalition of New York State (NHCC)  
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## A VISION

We are excited by the mission and promise of assisted living to allow people to have maximum independence and control over their lives and the ability to remain in place, even when they need more care.

However, this can be challenging and hard to accomplish. A three year study of assisted living in New York State we conducted identified the difficulties of fulfilling this promise. As a result, we began a project to work with the assisted living industry to move closer to making these ideals a reality. In order to advance this vision, we have written educational materials for both consumers and assisted living providers. There are four different guides:

- A guide for potential residents helps them choose an assisted living community where the goal of resident choice and decision-making power is a reality.
- A guide for people now in assisted living, helps them evaluate their residence in terms of this goal and suggests ways to work with staff and other residents to make it a reality.
- A guide for assisted living managers looks at the obstacles that might block this goal and suggests ways to overcome them.
- A guide for assisted living staff, who work directly with residents, helps the staff to make this goal a reality in the residents' everyday lives.

The purpose of these guides is to generate both discussion and action among consumers and providers about how to deal with any concerns raised and how to maximize choice, independence and the ability to remain in a residence as one becomes more dependent. We do not expect to see the promise of assisted living achieved overnight. This is a vision for the future. It is a work in progress.

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## NOTE TO THE FAMILY

**T**his guide has a special focus — promoting older adults’ rights to make decisions about their own 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 because of failing thinking abilities, you may become the official guardian or unofficial decision-maker. If so, all the ideas here can help you, as you use your judgment to guide your relative’s life.

Say your mother’s having some trouble thinking. Still, there may be times of the day when her mind works well. She might not be able to make a decision like whether to get cataract surgery, but she probably still has strong preferences about which clothes to wear and what food to eat. Even if her safety is your main concern, it’s still important to honor her preferences for what really matters to her.

As you visit assisted living residences, the staff may see you as the customer they want to please, so part of your role is to help them to focus more on Mom — and what she needs and wants. You can help by helping them to get to know her. Tell them which choices, hobbies, and other activities enrich her life most.

Carefully consider and discuss with your relative what he or she needs and wants to keep living as independently as possible. Identify your common goals, where you might disagree — and, if necessary, possible resolutions. Look to other resources, such as the residence staff or local Long-Term Care Ombudsman Program, to help find areas of agreement and settle any possible disagreements. You’ll be helping your relative achieve greater independence as a resident of assisted living.



## THIS GUIDE'S PURPOSE

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

**T**his guide helps potential residents choose an assisted living community where the goal of resident choice and decision-making power is a reality.

Assisted living is a promising option for seniors because of its philosophy — to promote residents' independence, and their rights to make decisions about their lives, as much as possible, while providing housing and tailoring services to meet their individual needs and preferences. But this promise is hard to achieve. It is important you have an understanding of the philosophy of each community you visit and how each will enable you to live your life the way you want.

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

**T**his guide will be most helpful to those who have the time to read it. Do not wait until there is a crisis to explore your options or to choose an assisted living residence.

## HOW TO USE THIS GUIDE

This guide will help you evaluate what you need and want — and decide which of the places you’re considering will suit you best.

The guide also highlights the basics of choosing an assisted living residence. But you should read widely to learn more about contracts, costs, payment options and assisted living services. Research the resources for help and the assisted living options available in your community and state. We’ve suggested where you can find more information at the end of the guide, including some “how to choose/checklist” guides.

## WHAT IS ASSISTED LIVING?



Generally, assisted living residences provide a combination of housing and supportive services for seniors who don’t need to be in a nursing home (for round-the-clock nursing and medical care) but do require more personal care and health services than independent living provides.

But be aware that the federal government doesn’t define assisted living, and states have developed their own definitions. Even within some states, different types of residences are called “assisted living.” When exploring your community’s assisted living options, you may find many different populations served and settings, accommodations, and services offered.

Some assisted living residences keep people with certain physical or mental conditions, while others may not accept them — and might ask people who develop such conditions to leave.

Settings vary widely — from small homes to big apartment buildings. Many are stand-alone assisted living residences, while others are connected to independent housing and a nursing home on the same campus.

Accommodations and services also vary. Some residences provide apartments with kitchenettes, while others offer private or shared rooms. In one residence, services may be limited to housekeeping and personal care, such as help with bathing and dressing; meanwhile, another may also offer other services such as physical therapy or transportation. 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 your whole spectrum of options. Do you still live at home? If so, before deciding on assisted living, find out whether you could 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's 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, here's another option to consider: 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 at home anymore or manage on your own as you once did. Or you may be anticipating when you might not be able to, and considering moving away from home or independent living.

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 or apartment — or even in independent living.



## PLAN AHEAD

Many people have to choose an assisted living residence in the midst of a crisis, so they don't have time to weigh their options. But it's best if you can prepare ahead before any health crisis forces you to make a quick decision. That way, you can take time to explore what you need and want, and be a careful consumer. You'll find the community that's best for you, and you'll help realize assisted living's promise — helping you to maintain control over your life and to make the residence you choose your home.

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? Can you choose something that is not on the menu? Does the activities program offer activities you enjoy? What housekeeping services are available and are they included in the monthly fee?

As with any choice of where to live, another important consideration is likely location. 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 key: a single apartment located close to an elevator is more desirable — and expensive — than a shared room farther down the hall.

Next comes price. Assisted living can be expensive. Some private long-term care insurance policies cover it, but Medicare doesn't. Certain states are starting to cover some services under Medicaid. Monthly fees may be the same for everyone, or set based on which services you need. But fees can rise at any time, and extra services may raise them, especially if they include hourly charges for assistance. The management of some residences also charges an entrance fee or requires a refundable security deposit.

## MAKE MANY VISITS

Try to make several visits to at least a few assisted living settings to decide which will best meet your needs and desires. Research your options by speaking to family, friends, and other resources in your area. The local Agency on Aging and the Long-Term Care Ombudsman program, which exists in many communities throughout the country, can provide information about how to find high-quality assisted living. The Ombudsman Program is a federal and state funded program that works to enhance the quality of life and care for assisted living and nursing home residents. Ombudsmen are advocates that resolve residents' complaints and educate consumers and providers of assisted living.

Try to visit a given residence 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.

## WHAT TO ASK

Use the table “Your Needs, Wants, and Questions” (on page 9) to write a list of questions in advance. Get copies of the residents' rights and rules, contract, price list, and floor plan to read closely later.

Make sure your state has licensed the residence. Ask specific questions about how they'll meet your individual needs for services — not only now, but also if those needs rise.

### QUESTIONS TO ASK the staff:

- Who draws up the Resident Service Plan (an individualized list and schedule of which services each resident receives, and when)? How involved is the resident and family in this process?



- If monthly fees are based on a service formula, how often is it reassessed? When fees rise, how far in advance do you notify residents?
- How stable is the residence financially? Ask for a copy of their annual report. Do a search on the Internet to see what reporting there has been on the company.
- Who decides about transferring residents within and outside the residence? Is a nursing home affiliated with or attached to the residence, and if so, may I visit it?
- How are grievances handled? Is there a Resident Council? Is there a Family Council? Who run the councils?
- How does the waiting list work? Is there a probationary period after a resident moves in?
- What happens in a medical emergency?

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.

Residents and their family members are other important sources of information. Ask them what they like and dislike about the place. Talk with residents who are outside or in the lobby, where they may feel free to give honest answers about whether there's enough staff and how active the Resident Council is.

## 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 dinner.

Some assisted living residents complain they aren't provided with real options, so they can't achieve real control. Instead, their residences' staff and management just select alternatives in advance and then offer them to residents.

### THE KEY TO CHOOSING A RESIDENCE

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

The management of assisted living residences often makes up house rules and structured routines to balance their competing demands as both group living settings (for residents) and workplaces (for staff). How, when, and how often things are done may result from staff levels and schedules. Specific times for bathing schedules, meals, visiting hours, and trip schedules for shopping or running errands may limit your options and chances to make your own decisions.

Before choosing a residence, you should explore which kinds of help you need and how you prefer to lead your life. Then use this assessment of your needs and preferences to ask questions about how well the staff can serve you. For instance, if you need help dressing and you 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 is right for you.

Try to be realistic about your needs. 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.

## FAMILY MEMBERS CAN HELP GET RESIDENTS' NEEDS MET

**I**f you're the relative of an older adult who is considering assisted living, you can help by remembering which activities he or she enjoyed most. Ask yourself: What did Dad like best? Then you can help him continue to thrive in assisted living, pursuing a path similar to what he would have chosen for himself if he were still living at home.

# YOUR NEEDS, WANTS, AND QUESTIONS

THIS IS A GUIDE — each person is unique and may need to ask different questions. Check each box that applies to you. (You may want to cut out or copy pages 9 and 10 for your visits.)

## What Do You Need? Do You Need Help...

- Walking?  Dressing?
- Eating?  Bathing?
- Toileting?

## What Do You Want? Is It Important for You To...

- Maintain your routines, such as deciding when to:
  - Get up?  Go to sleep?
  - Eat meals?
  - Bathe or shower?

## Questions to Ask

- Can I decide when I:
  - Get up?  Go to sleep?
  - Eat breakfast, lunch, and dinner?
  - Shower or bathe?

- Cooking?  Doing laundry?
- Housekeeping?  Reading?
- Writing?  Paying bills?

- Spend your time:
  - Cooking?

If there's a kitchenette, are the cupboards reachable?

If no kitchenette, what chances are there to prepare my own meals?

- Doing laundry?

Is there a laundry for residents' use?

- Keeping house?

Can I keep my own housekeeping supplies?

Can I get help doing my own laundry or housekeeping?

- Entertaining?

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? Books on tape?

Are written materials from the residence, such as the admissions contract, house rules, newsletter, in large print?

- Writing social and business letters?

Can someone from the residence help me write my letters?

- Doing something else? If so, what?

# YOUR NEEDS, WANTS, AND QUESTIONS

## What Do You Need? Do You Need Help...

Getting places?

Maintaining your involvement in your neighborhood and larger community, such as:

Your church, mosque, or synagogue?

Clubs and organizations you belong to or volunteer for?

And regular supervision from a doctor or nurse because of a medical condition?

Managing or taking your medications?

## What Do You Want? Is It Important for You To...

Go certain places, such as:

Supermarket?  Park?

Bank?

Department store?

Library?

Hardware store?

Museum?  Take trips?

Visit family and friends?

Staying involved with your neighborhood and larger community?

Be involved and have a say in your medical treatment?

## Questions to Ask

What transportation is available from the residence?

What options are there for individuals to schedule outings other than to 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?

What are the procedures if I decide to stay overnight with a friend or go on trips overnight?

What are my chances to continue my community activities, such as attending my place of worship, or clubs or organizations I belong to?

What other opportunities are there to engage in community activities?

What opportunities are there to be involved and have a say in my medical treatment?

Can I refuse medications, services or treatment?

## MAKE YOUR OWN DECISIONS

You also want to preserve your power to make decisions about the aspects of your life that matter most to you. It might be important for you, for instance, to decide whether to go for a walk by yourself, even if you have a chance of falling. It might be a priority for you to walk as best you can — even if your family or the residence staff thinks you'd be safer in a wheelchair.

It might be essential for you to decide whether or not to take a specific preventive health action. For instance, you may sometimes want to go off a special diet. Some decisions may involve weighing your desire to do something, such as going for a walk alone, with the possibility that you might raise your risk, like falling. Or you might like to smoke or have an alcoholic beverage.

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 things may limit you from living 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 the way they see their 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 it's possible you could fall. But the staff may not let you, because they feel that the danger of your falling is too great, or greater than you think it is. They may feel their job is to protect you and do for you, instead of helping you be as independent as possible. This may come from their own beliefs, or from your family's instructions, or from what they think an outside government regulatory agency requires. They may also be concerned about liability. However, don't take for granted that you must fall in line in the face of these possible limitations. Ask questions (some examples are given 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.

### ***Inappropriate Fear***

You might limit yourself from doing things for yourself or participating in certain activities because of the fear that you cannot do it or you will get hurt.

## 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

### KNOW YOUR RIGHTS

**K**nowledge is power. Your contract, admission agreement, and government regulations and laws establish rights for you. But you can't take full advantage of these rights if you're unaware of them. It's up to you to assert your rights.

and health oriented. All your life you may have done exactly what doctors have recommended, and you may feel that the details of life in assisted living are all a matter of a doctor's prescriptions. You may feel that the doctor or nurse "knows better" and assume they should or will make decisions for you. But in reality, many of the choices involved in assisted living have been under your control all your life, such as deciding on your own schedule. 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.

**QUESTIONS TO ASK** yourself and the staff of potential residences:

***Does frailty or a medical condition limit your choices and activities, such as walking or choosing food?*** If so, ask the staff:

- How do you deal with residents who have a history of falling, but who like to go for walks alone outside the building?
- How do you react to residents who occasionally eat foods not on their diet?

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

- Can I come and go as I please?
- Can I take a late night walk if I want?
- Do you believe the neighborhood poses dangers to residents?
- Can I smoke? In my room? In special areas in the building or on the grounds?
- Can I take an alcoholic drink? In my room, public areas, or the dining room?
- What if I want to do something my family deems unsafe?
- Are there government rules that the management believes limits my ability to do things that might be unsafe for me?

## HELP PLAN YOUR CARE

You probably want your independence maintained as much as possible. To do so, you may need to receive services that are tailored to meet your individual needs. One of the benefits of assisted living is getting the help you need so you can do more for yourself and enjoy more of your favorite activities than you could at home alone.

Assisted living residences often have a Resident Service Plan that documents what staff will do for residents and establishes a schedule for providing this help. The Resident Service Plan results from a planning process that tries to identify your needs for help. If you need to communicate in a language other than English, for instance, that should be in your plan. It's important for you to see this plan — and to help develop it — to ensure that it either reflects your preferences or is changed to do so.

## WHAT TO LOOK FOR

Besides giving you a chance to ask lots of questions, each of your visits should include a tour of the building, grounds, and neighborhood. Here's what to look for. (You may want to cut out or copy pages 13 through 16 for your visits.)

### *Entrance*

- Does it allow easy access outdoors and to the rest of the building?
- Can I enter from the street without using any 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 \_\_\_\_\_

### *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?

## SUBSTANCE TRUMPS SURFACE

**T**ry not to be distracted by flashy facades. Instead, focus on whether the physical environment — and the community of staff and residents — will promote or limit your independence, depending on what's important to you. In the long run, the quality of services will matter much more than whether the lobby looks fancy.

CUT HERE

- Can I arrange the furniture as I like?
- Do I have a key to my unit? Can I lock the door from the inside?
- Who else has access to my unit?
- Do I have individual control of the temperature?
- Can I have overnight guests without checking with management?
- What storage space is available?

Notes \_\_\_\_\_  
\_\_\_\_\_

### ***Kitchen***

- If there is a kitchen or kitchenette, can I reach the cupboards?
- If there's no kitchen, what chances are there to prepare my own meals?

Notes \_\_\_\_\_

### ***Bathroom***

- 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 \_\_\_\_\_

### ***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 \_\_\_\_\_  
\_\_\_\_\_



## **Common Areas**

- Are there common areas that give residents a variety of different activities — lounges, sitting areas, library, and facilities to prepare and serve meals to friends and relatives?
- Are there quiet areas to be alone other than my room?
- Is there a laundry for residents' use?

Notes \_\_\_\_\_

## **Hallways**

- Are there handrails?
- Is the lighting adequate?
- Are the floors non-skid?
- Is it easy to find my way around the building?
- Are there wheelchair-accessible public telephones, with writing areas and loudness control?

Notes \_\_\_\_\_

## **Lighting, Layout, and Physical Condition**

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

Notes \_\_\_\_\_

## **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?
- Are tables available?

Notes \_\_\_\_\_

## **Staff**

- Do staff members talk to residents by name?
- Do they treat residents with dignity and respect?
- Do they really seem to care about the residents? Or do they ignore residents, or seem patronizing with them?
- 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 translate my needs and preferences to others?
- Is a nurse on staff?
- Do doctors visit periodically?
- Can I continue to use my current doctor?

Notes \_\_\_\_\_  
\_\_\_\_\_

## **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 \_\_\_\_\_

## **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?

Notes \_\_\_\_\_  
\_\_\_\_\_

## WHAT TO READ

Take plenty of time to read and review written information on resident choice and control and the ability to remain in the residence. Ask the management for a copy of their house rules and policies — and even their financial reports and any inspection reports on the residence. 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 you'll sign after you decide to move to a particular residence. Take it home with you at the end of your visit, and examine it thoroughly (with the help of an AARP booklet<sup>1</sup>) before signing it. You might also get a lawyer's help.

## 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, taking into account its location, price, and ability to meet your needs and preferences. If you have to move away from that setting, another place may not share these features, which you value. And you'd miss the friends you'll have made and the staff you'll know and who'll

know you. Research shows that when older people are moved from place to place, especially when their health is failing, they're more likely to become sicker and confused.

## QUESTIONS TO ASK the staff

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

- How much staff is there? What are their qualifications?
- Are therapeutic programs and assistive devices available?
- Can you adapt my apartment or room for me if I become more dependent?
- What disabilities would cause me to move?
- What happens if I become incontinent (or need a wheelchair, oxygen, I.V.)?
- Will I have to move my room or apartment if I become more dependent?

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<sup>1</sup> AARP *Navigating Your Way to a Quality Assisted Living Facility*, 2000

***What if I can't afford the extra services I'll need if I grow 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 pay for the extra costs of your services. If not, you'll likely be asked to leave the residence or be transferred to a setting with a higher level of services.

***Will any government regulations make me leave the residence if I get too frail?***

State and local government agencies that oversee assisted living may have rules that make you leave the residence if you get 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 local Ombudsmen office 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 addressed this situation?

Ask yourself:

***Do I want to be able to stay in the residence no matter how frail I become?***

While most people would prefer to stay where they are as their health deteriorates, the managers of many assisted living residences may make you leave if you become more dependent.

## ACHIEVE THE PROMISE

Best wishes in choosing an assisted living residence where you can maintain your independence as much as possible. As you proceed in your search, we urge you to keep informing yourself by consulting as many sources as you can. This guide is only one of many resources. For more, see “What to Read” and “Resources” on pages 17 and 20.

If you decide on an assisted living residence, please see another of our guides, called “Residents Guidebook for Assisted Living: Towards Achieving Your Independence”. As that guide describes, there’s a lot you can do to ensure that you lead as independent a life as possible in assisted living:



- On your own, you might negotiate one on one and talk to the staff about changing any rules that hamper your independence.
- But you have the most power as part of a group. Resident Councils give residents a chance to talk about these issues as a group and have some say about how the residence is run. There might be widespread dissatisfaction with the food, or a schedule. If so, a Resident Council could reach a consensus about changing it, and talk to the residence’s management about making the change. That result might not please every resident, but it would serve more of them.

We hope this guide helps you become a more informed — and careful — consumer.

## RESOURCES

### **AARP ( formerly American Association of Retired Persons)**

(800) 424-3410 [www.aarp.org](http://www.aarp.org)

601 E Street, NW, Washington, DC 20049

A national organization for people age 50 and older. Contact AARP to obtain a copy of these free materials:

- *Navigating Your Way to A Quality Assisted Living Facility* – Will help you read and understand assisted living residence contracts.

- *Assisted Living: Weighing the Options*

An introduction to what assisted living is and what to consider when exploring assisted living as an option.

### **Administration on Aging (AoA)**

(202) 619-0724 [www.aoa.gov](http://www.aoa.gov)

Washington, DC 20201

An agency in the U.S. Department of Health and Human Services, whose mission is to promote the dignity and independence of older people. AoA's website provides links to State and Area Agencies on Aging.

### **American Association of Homes and Services for the Aging (AAHSA)**

(202) 783-2242 [www.aahsa.org](http://www.aahsa.org)

2519 Connecticut Avenue, NW

Washington, DC 20008

A national organization of not-for-profit nursing homes, continuing care retirement communities, assisted living facilities, senior housing facilities, and community service organizations. Their website has a sample assisted living resident contract you can read — and can help you find AAHSA-affiliated assisted living residences in your community.

### **Assisted Living Federation of America (ALFA)**

(703) 691-8100 [www.alfa.org](http://www.alfa.org)

11200 Waples Mill Road, Suite 150

Fairfax, VA 22030

A national organization of for-profit and not-for-profit providers of assisted living, continuing care retirement communities, independent living, and other forms of housing and services. Locate ALFA-affiliated assisted living residences in your community. Their website has a consumer checklist and articles of consumer interest about assisted living.

### **Consumer Consortium on Assisted Living (CCAL)**

(703) 533-8121 [www.ccal.org](http://www.ccal.org)

2342 Oak Street, Falls Church, VA 22046

A national consumer advocacy organization dedicated solely to the needs and rights of assisted living consumers. Visit CCAL's website to obtain the booklet:

- *Choosing an Assisted Living Facility: Considerations for Making the Right Decision, 2nd edition*

This booklet provides questions consumers need to ask in a wide range of areas when choosing an assisted living residence.

### **Eldercare Locator**

(800) 677-1116 [www.eldercare.gov](http://www.eldercare.gov)

A national toll-free directory of local services for seniors.

### **Family Caregiver Alliance**

(415) 434-3388 [www.caregiver.org](http://www.caregiver.org)

690 Market Street, Suite 600

San Francisco, CA 94104

A non-profit support organization for caregivers. Their website provides information and resources for family caregivers of the cognitively impaired, including information about assisted living.

### **National Center for Assisted Living (NCAL)**

(202) 842-4444 [www.ncal.org](http://www.ncal.org)

1201 L Street, NW, Washington, DC 20005

The assisted living voice of the American Health Care Association, a national organization representing long-term care providers.

Call (800) 628-8140 to obtain a free copy of NCAL's brochure, *A Consumer's Guide to Assisted Living and Residential Care*. This brochure has a checklist and a "Cost Calculator" worksheet to record the estimated costs of assisted living services. You can also obtain the brochure through the website. Also locate NCAL affiliated assisted living providers through the website.

### **National Long Term Care Ombudsman Resource Center (ORC)**

(202) 332-2275 [www.ltombudsman.org](http://www.ltombudsman.org)

1424 16th Street, NW, Suite 202

Washington, DC 20036

ORC provides support and training to Ombudsman programs nationwide. Locate the ombudsman in your state through the website.

# ACKNOWLEDGEMENTS

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THE COALITION OF INSTITUTIONALIZED AGED AND DISABLED (CIAD) is a non-profit, consumer-led organization of adult home and nursing home residents and residents' councils. CIAD provides residents with the information and skills they need to advocate for themselves, and works to improve the quality of their lives and their care. CIAD organizes residents into resident councils, educates residents about their rights, and promotes their participation in the affairs of their own residences as well as broader public policy issues.

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THE NURSING HOME COMMUNITY COALITION (NHCC) is a statewide coalition of consumer, professional and civic groups that work to improve the quality of care and life for residents of nursing homes and assisted living residences. NHCC has produced a number of studies on nursing homes and assisted living and has written and distributed educational material for consumers and providers.

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