Encouraging Resident Independence and Choice in Assisted Living:

Ideas for Direct Care Staff



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INTRODUCTION

Most seniors choose an assisted living community because they can no longer live at home but they wish to avoid the institutional setting of traditional nursing homes. They expect that assisted living will provide a more home-like setting in which they can maintain independence – their ability to make decisions and have control over their everyday lives. In short, seniors hope to find a place where they can, as much as possible, live as if they were in their own home.

You can make a difference. Seniors, as with any individuals, may experience hopelessness and

depression when they do not feel in control of their lives. Your interactions with residents can make a big difference in how they feel about themselves and their lives.

Your work is important. You are one of the most important people in a resident's life. You can help a resident get what they want and need. Your care for residents can help them remain as independent as possible. You can help them have control over their everyday life and make sure they can do, as much as possible, what they want to do.

Note:

- It is not necessary to read this guide in one sitting.
- We hope this guide will be used as a reference - a booklet to go back to over time, looking for ideas.
- Not every idea will work for you or your assisted living.
- Select the ideas you believe will work for you and the residents.

Your work can be challenging. We know that you

are very busy. You do many things at once. You are always on the move. You may not be sure how you can take on new ideas or approaches. You may not be sure you have the time.

This guide can help you. It has **lists of ideas** that we believe will help you to do your job and meet these important resident needs.

This guide includes "Cases" which detail events involving caregivers. We ask you to consider whether these cases can apply to your work. The guide also includes "Scenarios" which are fictional accounts to elicit discussion and action. We encourage you to discuss these with other staff and management.

Many of the ideas will be effective for residents with physical problems and those with cognitive impairment. The guide includes a special section focused on caring for residents who have more advanced dementia.

We know that you cannot do this alone. We have also written <u>a guide for management</u> so that you can work alongside each other in encouraging resident independence and choice. We hope that you will discuss the thoughts in this guide with management. **Good luck and thank you for your dedication.**

Choice and Control

What Do Control and Choice Mean to You?

Please list those things that you can decide for yourself each day. For example, do you decide when to go to sleep? If so, put that down on your list. You might put the following things on your list: bedtime, what to eat, when to eat, who to eat with, when to bathe, whether to shower or bathe, what to wear, whether to stay in bed all day on a day off, where to live, activities you want to do such as go to a movie or shopping or read a book, go out with friends or be by yourself, and many, many more.

If you could not make these decisions - if other people made them for you - how would you feel?

How Much Choice and Control Do Residents Have in Your Assisted Living Community?

Look at the list of everyday decisions you make again. How many of those decisions can or do **the residents** make?

- Can they decide when to get up and when to go to bed?
- Can they decide to go for a walk when they want to?
- Can they decide to take a bath rather than a shower and when to take it?
- Can they control the temperature in their room or apartment?
- Can they use their own furniture and arrange it in any way they like?
- Can they have a pet if they want to?
- Can they choose what to eat at each meal, when to eat and who to eat with?
- Do they have a place to cook if they want to?
- Do they have a place to entertain family and friends?
- Can they go somewhere whenever they want to go?

There may be many reasons why the residents in your community lack the freedom to make the same decisions you do. A resident with dementia may not be able to go out whenever they want. Residents in an assisted living in rooms without separate temperature controls may not be able to control the temperature. However, there are many things that all residents can and should have control over in any residence.

Look at your list of things you decide each day. Think about the residents and put a check next to those items on your list that you believe the residents **should** or **could** have free choice about. If you feel the residents don't have some choices that they should, don't worry about whether it seems possible right now. Indicate which decisions you think they should be able to make. What decisions would you want to make if you were an assisted living resident?

What Might Stand in the Way of Resident Choice and Control in Your Assisted Living Community?

You are working here because you like caring for the elderly. You want to help residents do what they want to do. Yet there may be barriers making your job even harder than it is.

- Staff shortages can mean there is less time to help residents make choices.
 - A resident may want to go to an activity outside the residence, but there is no available staff to take them.
 - A resident may want to stay asleep until 10 AM, but there may be so many residents who need help dressing that you do not have the time to come back later.
- The resident's family may not want the resident to make their own decisions. You might feel like you are in the middle. Who should you listen to?
- Some residents may not speak English and you may not understand them.
- Because your job is so difficult sometimes you might limit a resident's freedom to make things easier for you. For example, some residents may need help with eating. It may be easier for you to group residents together for meals, rather than allowing them to decide where to sit.

"We work around their schedule. It is not about us. We are here from 7 to 3:30. They live here 24/7. If we knock on their door and say, bath time and the resident says, 'I don't want to take a bath.' Do you want to take it later? Okay, later. We have no problem. We come back later."

-Resident care assistant

Encouraging Resident Choice and Control, and Making Your Life Easier

You can make a difference. How you do your job can encourage more resident choice and control. It can also make your job easier.

You may be thinking: "Right. How can I help residents have choices and control? I am too busy. I must take care of many residents. It is impossible."

The ideas below can help you encourage resident choice and decision-making. Many will also make things easier for you.

Get to know the resident. Speak to your residents about what their life has been like. Get to know their routines, and their likes and dislikes.

- **Getting to know residents well will help you.** Some residents, angry or upset at being unable to live at home, may take it out on you. The more you speak to residents, the more they will see you as a person. They will be less likely to take their dissatisfactions out on you. Residents complain or get angry in part because of frustration as they cannot do what they want. By making this possible for them, you may find that they will act differently.
- **Encourage residents to tell you how best to care for them.** Often, the resident knows the best and easiest way to be cared for. Develop a partnership with the resident. Ask them about their care preferences.
 - A resident is likely to know how best to be bathed to avoid pain or discomfort. For example, a resident who needs help getting dressed may know that it is easier to put their left arm into the sleeve of a sweater first.

Encouraging residents can make your job easier and while also saving the resident's time. Read the scenario below. Would you have responded?

Scenario: Left Foot First

You begin to help a new resident put on his pants. You help him put his right foot in and then pick up his left foot. He pulls back and says, "That hurts. It is better if you put my left foot in first." You listen and you and the resident find dressing easy, quick, and painless.

Encourage residents to choose their daily routine.

- If a resident does not want to get up early and needs your help to dress, give them time by taking care of other residents who do not mind getting up early.
- If a resident wants to bathe in the evening, help arrange for this by switching other jobs from evening to daytime. Work with other caregivers to make this happen.

Scenario: Get By With a Little Help

You take care of 15 residents. Some need a lot of help getting ready for the day, others need less. You meet with each resident and tell them you want to develop a schedule with them. You ask them when they would like you to come in to help them and ask if they have any activities they need to get to. You work out a schedule that meets most of each resident's demands. You ask those who need little help to choose their clothes at night, which saves you time in the morning. You go first to those residents who want to get up early so the other residents can sleep.

Here too, you will benefit. You are making the resident feel more in control. And a resident who can keep a schedule they have had for many years is a happy resident. They are less likely to become frustrated and take things out on you. If you need help arranging this, speak with your supervisor or management.

Scenario: Skip It

A resident who needs help bathing wanted to skip her bath or take it later because she wanted to go to an activity scheduled at that time. You and the resident develop a schedule that works for you both. By shifting things around, you can bathe her close to the end of your shift.

Encourage residents to choose things for themselves.

- If you are helping a resident dress, go to the closet and ask the resident to choose what they want to wear. If you are too busy in the morning, try to set this up with the evening resident care assistant the night before.
- Encourage the resident to decide what types of activities they want to be involved in and help them get to those activities.
- If your residence has a resident council, encourage the residents to join. Assist them, if they need help, in getting to meetings.
- Help families understand that the resident (who is capable) has the right to decide things for themself. You cannot do this by yourself. Management must first work with families to help them understand this. As you work with families who insist on making decisions for the resident, explain to them that this is not good for their relative. The family may think they are protecting their loved one. However, they may be causing their relative to become depressed and more dependent. In addition, if your state has regulations that require you to listen to the capable resident over family, let the family know. If you are having problems with this, notify your supervisor.
- Make management aware of any language barriers or other communication challenges. If the resident cannot make themself understood, speak to management to discuss how to deal with this issue.

Case: Video Review

With help from management, residents in an assisted living community decided to show how they were routinely ignored by direct care staff. Residents filmed several role-plays, playing the parts of both resident and staff. One video, later used in staff training, showed a care assistant helping a resident put on a shirt as the resident says, "I don't want that shirt. I want the blue one." The care assistant continues to dress him, acting as if she did not hear. The video was a revelation. After viewing the video, staff indicated they were unaware they were not listening.

INDEPENDENCE

What Does Independence Mean to You?

Pick up your pencil and paper again. Write down things you can do for yourself. Think about your workday and days off. Think about what you do in the morning, daytime and at night. Do you shower or use the bathroom by yourself? Cook? Drive yourself to work? If so, put them down on your list. Write the things that you can do without the help of others. If you needed help to do some of the things on your list, how would you feel?

How Independent are the Residents in Your Assisted Living Community?

Look at your list of things you can do by yourself. Which of those do you help residents with? Walking? Using the bathroom? Bathing? Dressing? Due to poor health, some residents may be dependent on you for many things. Can you help them gain independence in some areas? What could you safely do to encourage resident independence?

What Might Stand in the Way of Resident Independence?

- Encouraging residents to be as independent as possible may be limited by a desire not to make things too difficult for yourself.
 - It may be easier to brush a resident's teeth than take the time to help the resident do it themself.

"[I think about] life losses. Even if I have no place to go, if my car is not outside in the driveway, I'm crazy...So, with a lot of people [here], you hear the same story: 'I was down in Florida...[now] my condo is gone' and about all the wonderful times they had down there [when they had] a car...Not having their car and the freedom to go shopping and just pick up and go whenever you please...It is a loss for them."

o It may be easier to give someone a bath or shower than to arrange things so the resident can wash themself with assistance.

However, taking the time in the beginning will save time later. Giving residents time to do things themselves may require extra time in the beginning, but investing that time can help them gain independence and help you save time in the long run.

- Family members may not want their relative to be as independent as you believe they could because they are so concerned for their relative's safety.
 - o Are you concerned about following their wishes?
- Some residents may be afraid of doing things you believe they could do safely.
- Residents who do not speak English may find it hard to communicate.

Case: Attention Please

In one assisted living, some residents who saw that those who needed help were getting more attention from the staff than they were, so they asked for help they did not need. The caregiver sensed that they felt neglected, so she found time to give these residents attention by sitting and speaking with them. They stopped asking for help they did not need.

Encouraging Resident Independence

Many residents have physical problems or cognitive impairment. Many of them depend on you because of this. You are in position to help these residents be more independent than they would have been if they remained at home.

Important Note: Find out from supervisory staff how independent the residents can safely be in different areas such as: dressing, bathing, eating, walking, etc. Then you can work on ways to encourage them to be as independent as they can be.

We know you work hard every day and that you probably go home exhausted. How can you encourage independence when your plate is already full? Though it may seem that doing things for the resident will save you time, you and the resident will benefit in the long run by encouraging independence. Review the ideas below.

"When we keep residents feeling more independent, they are less aggravated."
-Resident care assistant

- Encourage the resident to do it themself.
- Make sure the resident has what they need to be as independent as possible.
 - Walkers, canes and wheelchairs should be readily available. If they're not available, the resident will have to call for help.
 - Make sure that any devices the resident needs to eat are by their side. If they're
 not, the resident will be unable to feed themself and will need you by their side.
- **Support the resident who is afraid.** If you know that a resident can safely walk without help for a short distance, or can safely wash themselves once in the shower, but is afraid, reassure them him that you will be with them help if needed.
- Encourage families to support the resident's independence. Help families understand that if residents do not do things for themselves when they are able to, they will quickly become more dependent. Help the family feel comfortable by asking a supervisor to explain that it is safe for their relative to be independent.

RISK-TAKING

Risk-taking is a difficult issue. You want to help people and keep them safe. You do not want them to harm themselves. However, you know how you would feel if you were not allowed to do something you wanted to do.

Do You Ever Take Risks?

Do you ever do things someone else might consider unsafe or dangerous? Do you smoke? Sit in the sun too long at the beach? Eat more than you should? Do you go on adventurous trips? Have you ever gone scuba diving or mountain climbing?

In thinking about your answers to these questions, consider:

- What happens when you do these things? Do you know what could happen?
- Do you do them anyway? Why?
- How would you feel if you were told not do the activity, or if someone stopped you from doing it?

Do the Residents Ever Take Risks?

What kinds of things do the residents do or want to do that you consider unsafe? Make a list.

- Do they want to go outside even when you think it is too cold or hot?
- Do they want to smoke?
- Do they want to go shopping on their own even though you feel they need help?
- Do they sometimes want to eat fattening, salty, or sugary foods when they are obese, have heart problems, or are diabetic?
- Do they want to go for a walk outside, even though you feel they are too frail?

If the residents are not permitted to do things you consider unsafe, how do you think they feel? Do the residents agree that the action is unsafe? If it really is dangerous, why do you think the residents might want to do it anyway?

Scenario: Danger Zone

A weak resident wants to go to the store along a busy highway. You tell him that you think it is dangerous. He is very upset and wants to go. You go to your supervisor and ask what you should do. She knows that the resident understands what may happen. She suggests that you ask if you can go with him. You ask the resident, he says yes.

An Environment Where Residents Can Do Things You May Consider Unsafe

Only management, with the resident (and family, if the resident is not capable), can make decisions in this area. They must first decide if the resident can understand what may happen if they take a risk. They also are the ones who must decide if the action is dangerous. Then they must decide what to do if it is dangerous.

However, you play an important role in this situation. You know the resident best. You know how important it is to the resident to do what they want. You may know how well they can understand.

- Your role is to bring these issues to management.
- You should also go to management when you have problems.
- You should attend any service plan meeting where risk-taking is discussed so you can let others know what you know about the resident.

PARTICIPATION IN DECISION-MAKING IN THE ASSISTED LIVING COMMUNITY

How Much Do You Participate in Your Community?

What decisions do you make about your community? Do you vote? Are you on a tenant board? Are you a member of the PTA?

Perhaps as a member of the PTA you help develop activities for your child's school. You might fight for more traffic lights or less noise in your community as a member of a community group. These decisions, although not about your everyday routines, may have a major effect on your life. Lessening noise may help you sleep. More traffic lights may keep you and your family safe.

- How would you feel if someone told you that you could not participate in your community?
- How would you feel if you could not have a say in any of these things?
- How would you feel if others decided these things for you?

How Much Do the Residents Participate in Decision-Making in Their Community?

The residents are a part of their community, the assisted living, in the same way that you are a part of yours. What decisions do they help make about the assisted living community in which they live? Do they bring any suggestions and concerns about policies to you for consideration?

- If there is a Resident Council, does it participate in decisions made by residents or does it merely raise issues?
- Does it participate in choosing decorations for the residence?
- Does it participate in deciding mealtimes or the selection of food served?
- Does it participate in staff training?
- Do the council or individual residents help interview and choose staff?

What Might Prevent Resident Participation in Decision-Making?

- It may be difficult to help residents become decision makers and/or advisors either individually or through a resident council. Some individuals have not had a lot of experience with decision-making in their lives.
- Some residents may not seem interested in participating.

Scenario: Every Voice Matters

A resident is always complaining about the food. You know that a small committee of residents has been set up to work on improving the food, and ask the resident if she would like to join. When she tells you she does not want to because she feels no one would listen to her, you respond by saying that her opinions are important and offer to help her get to the meetings. You also offer to introduce her to the other residents if she feels uncomfortable going to the meeting on her own.

Encouraging Resident Participation in Decision-Making

You are in a wonderful position to help residents participate in their community. Many residents will turn to you for encouragement. Here are some ways you can help them:

- Encourage residents to become active in the resident council if there is one.
- Help the resident council in its work, if asked.
- Help residents participate on small committees that can make decisions if management has set these up. For example, develop a schedule with a resident to make sure that they can make the meeting times.
- If a resident has an idea about making changes in the residence, encourage them to share the idea with management and/or the resident council.
- If you know of any resident that may want to join a committee working on residence issues (such as staff training, menus, or decoration), encourage them to join. Recommend them to the council.

PARTICIPATION IN THE OUTSIDE COMMUNITY

Think about ways in which you are part of your neighborhood or community. Do you enjoy dining out or going out with others? Do you go to temple, church, mosque, or synagogue? Do you go to the store or a beauty salon or barbershop? Do you go to the movies?

How would you feel if you rarely left your house? The residents are a part of their community just as you are a part of yours. What activities do the residents take part in outside the community?

- Do they go to temple, church, mosque, or synagogue?
- Do they go to the movies?
- Do they go shopping?

Would you want to do these things if you lived here? What community relationships or activities would you want to continue if you lived here?

Scenario: Field Trip

You try to get the residents to go outside on a trip but few are willing to go. When you ask why they don't want to go, they say that there is no reason. However, you think they look fearful and so you follow up and find out that they are afraid they will get too tired. You reassure them that you will be there and help them find a seat if they need one. You plan the trip so that there a number of places where the residents can sit if necessary.

What Might Stand in the Way of Resident Participation in the Outside Community?

- You may be afraid that more frail residents will get hurt if they leave the residence.
- It may seem too difficult to arrange for them to go out.

- It may seem too expensive to management. The residence may need staff to go along or may need to supply transportation and may consider that too expensive.
- Residents don't seem to be interested or seem afraid to go out.
- Encourage your residents to go into the outside community. Talk about your experiences outside the residence.

THE COGNITIVELY IMPAIRED RESIDENT

For many of the residents who are at the beginning stage of dementia, the ideas listed above will work. For others, modifications will be needed.

- Let residents wander if they want to and avoid telling them to sit down. Develop ways for them to wander safely.
- Structure a small group activities program to help keep these residents busy and interested.
- Don't tell them they can't poke around in different things. Set up situations where they can look through things without disturbing others.

Cases: Shooting for the Stars

- Residents complain that another resident is entering their room at night. She just stands and looks out the window. The caregiver reviewed the resident's information and learns that she used to be an astronomer. The caregiver figures out that she must be looking at the stars and then speaks to management about whether they could buy an inexpensive telescope. They agree, and the resident is set up with the telescope at a window. She is very happy looking at the stars and other residents are no longer disturbed.
- It was snowing very hard and a resident with Alzheimer's wanted to go outside. Staff asked her to wait until it stopped snowing. She refused, saying she wanted fresh air. Staff figured out a way to help the resident do what she wanted safely. The staff person asked her to get her jacket, gloves, and boots and then took her out to a wraparound porch. The resident stood there, saw the snow, and got her fresh air. Staff said, "I was able to let her do what she wanted to do in a safe way. It makes you feel good."

Cases: The Power of Patience

- A caregiver tells a resident that it is time to shower but the resident gets upset and yells. The caregiver leaves for a half hour and then returns, but the resident is still not ready and gets upset again. The caregiver stops by 30 minutes later and the resident is ready then. The caregiver is happy that the resident made the decision herself and that, as a result, helping the resident bathe will be much easier. She realizes that it is better to wait until this resident is ready than to waste time forcing her. The resident is happy as well.
- Some female residents with dementia carry handbags even if they're
 not going anywhere. In one residence, residents were carrying heavy
 pocketbooks and a resident care assistant urged them to put them
 down. Another resident care assistant told the first resident care
 assistant to let them be. "It is important to them to feel that they are
 doing things they have always done."

Many cognitively impaired residents wander, explore, and like to poke through different items. Rather than try to stop this behavior, encourage their independence. Find ways that they can do the things they want in a way that does not impose on other residents and their belongings. **You will find that it is easier for you to allow them to do what they want than to try to stop them.**

- Encourage residents to make decisions about their everyday life by learning as much as you can about their choices of times for getting up, going to sleep, etc.
 - Speak to families and friends.
 - Observe the resident.
 - If you set a time for personal care and find that the resident is not ready, back off and come back later. Your work will be much easier and faster if you are not fighting the resident as you care for her.
- Encourage residents to maintain their identity.
- Limit choices to two.
 - Rather than simply asking the resident with significant dementia what they want to eat, as you might with those who are capable, ask they want chicken or fish (choosing two types of food that you know they like).
 - Have healthful snacks available so they can help themselves.

You might find that you have helped these residents to feel content. In addition to making the resident's life better, you might find that your job has become faster and easier.

Many residents with dementia can maintain significant independence and choice with your help. As you care for them, you can consider ways to support them by setting up situations for their success and coaching them to live life to their fullest.

Case: Telephone

A resident who used to be a nurse keeps answering the phone on the residence floor and acting as if she is taking doctors' orders. People are upset because they do not want her on the assisted living's phone line. The caregiver arranges for another telephone so she can pretend to talk all she wants.

- To encourage independent eating, you may need to get the eating motion started by starting the feeding.
- You may need to put the toothpaste on the brush and start the brushing motion before the resident will take over.

Although this may take more time at first, it will save you time in the future.

REMAINING IN PLACE IF ONE GROWS MORE DEPENDENT

How Do You Feel When You Have to Move?

If you became sick, would you want to move out of your home? If you moved into a residence such as the one where you work, would you want to move again if you became even sicker? Think about when, in your life, you had to move.

Was moving to a new place an easy thing to do?
 What were some of the problems you found? Making new friends? Adjusting to a new place and new routines? Going to a new school? Finding new places to shop?

How Do You Think the Residents Feel About Moving?

- Think about new residents who come to the residence. What kinds of problems have they had getting used to their new home?
- Are the residents able to remain in this residence, if they want to, no matter how dependent they may become?
- If they must move, how do you think they feel about it?
- Why would they want to stay?

Scenario: Setting up Shop

A few residents in wheelchairs want to go to an activity. You stop in a few minutes early and make sure that room is set up for them to find a place where they can sit comfortably. You also make sure that they have enough room to enter and leave without disturbing anyone.

What Might Stand in the Way of Residents Remaining if They Become More Dependent?

Most individuals would prefer to remain in the residence even if their health gets worse. When they move, they lose important support like their friends and staff in the residence. And, when frail seniors move from place to place, they may become confused and even sicker. The following are some possible reasons a residence may not permit such individuals to stay.

- The more independent residents (and/or their families) may not want to be with residents who are becoming more dependent physically or mentally.
- Management may not want the residence to "look like a nursing home."
- Management may not feel it can care for residents that are more dependent.
- Management may feel that state regulations will not allow these residents to stay.

Developing a Community Where Residents Can Remain as They Grow More Dependent

To keep the home from looking like a "nursing home" and to ensure that independent residents are not disrupted, you could:

- Be prepared to help deal with conflicts between independent residents and those with mental or physical problems by being ready to get involved if necessary. For example:
 - Help to quiet down a resident with dementia who is agitated by redirecting them to an activity they like or a place that they find comforting.
 - Clean up a urinary accident quickly.
- Be prepared to help a mentally or physically dependent resident take an active part in activities without affecting the quality of life of the less impaired residents. For example:
 - Make sure that a resident in a wheelchair has room to move around.
 - Make sure that a resident with dementia joins other residents for appropriate
 activities at times that are good for them. They will disturb others if they come at a
 time when they are upset or if they go to an activity they cannot do or understand.

This will help you as well. For instance, residents with dementia who are more restless later in the day will make your work much harder if they are involved with activities with independent residents at that time. You may find that you need to spend time and energy trying to quiet them down or help them leave.

Scenario: Bathroom Break

You notice that one of the incontinent residents is moving around in an unusual way. You know that this is the time she usually is taken to the bathroom. You quietly enter the room where the activity is taking place and ask if she wants to go to the bathroom.

Anticipate possible outcomes. If one of the residents has urinary accidents, remind or take her to the bathroom before joining others. This may help you as well. You may be less likely to have to clean up an accident.

Thank you for thinking about the ideas in this guide. We hope that they will help you to improve your residence and better allow residents to maintain as high quality of life as possible. We hope they will help make your job easier and happier, too. We commend you for making the effort to enhance the experiences of the residents.