



# The National Long-Term Care Ombudsman Resource Center

## WORKING WITH FAMILIES: TIPS FOR EFFECTIVE COMMUNICATION AND STRATEGIES FOR CHALLENGING SITUATIONS

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## I. INTRODUCTION

The goal of this paper is to assist ombudsmen in working with families or legal representatives.\* Ombudsmen work with families in a variety of ways. An ombudsman may help a family member with self-advocacy or respond to a complaint from a family member, depending on the resident's wishes. Since the resident is always the ombudsman's client, the role of the ombudsman can perhaps be best described as working for residents and working with families.

This paper is designed to provide tips, resources and strategies to help ombudsmen improve their skills in working with families. It reviews key communication techniques that are important for ombudsmen in their interactions with and communicating their role to families. The paper also presents a range of materials for ombudsmen to use to help family members enrich their communication skills related to problem solving, inform them about their rights and the facility's responsibilities, and teach them how to self-advocate. Additionally, this paper provides examples of challenging situations and strategies for assisting families during those situations.

*\*The term "family member" is used in this paper; however, these communication techniques, advocacy tips and resources are also applicable when Ombudsmen work with a resident's legal representative.*

## II. IMPORTANCE OF WORKING WITH FAMILIES

There are several reasons why ombudsman work with families is critical. When a resident is incapable of making decisions and a family member is the legal surrogate and complainant, the ombudsman needs the consent and guidance of the family member in order to move forward.

Aside from working with families for legal reasons, an ombudsman can gain valuable and helpful insight and information from family members. Relatives can have a lifelong knowledge of the resident – her values, preferences, social history, concerns, what's important to her, significant events in her life, and more. Families can share important observations and make useful suggestions based on their experience with the resident. In some cases, such information can shed light on what's causing a problem and assist in crafting a solution, particularly when the resident is unable to communicate on her own behalf.

As well as learning from family members, one ombudsman noted that learning about family members can be helpful too. She reported that knowing about a family, such as the roles family members play and family dynamics can help the ombudsman better understand the resident and the situation. She added, "to serve residents well, you need to know about their family."

In some instances, it is important for ombudsmen to work with families because the resident needs or wants family support. For example, a resident may not feel comfortable taking action without encouragement or support from key family members. In other situations, concrete steps and actions by family members are needed, such as a daughter agreeing to call the resident every day at a certain time to calm the resident when she becomes agitated or family assisting a resident who is transitioning from the nursing home into the community. Making sure that family is involved may be essential for complaint resolution on behalf of a resident.

Taking the time to educate and empower family members allows families to address problems on their own, thus needing less assistance from the ombudsman. One ombudsman said that working with families on self-advocacy “makes the ombudsman’s job easier” and gives an ombudsman more time to help other residents who don’t have family to advocate for them. Additionally, when families view the Long-Term Care Ombudsman Program (LTCOP) as a helpful resource they may promote the LTCOP within the facility and the community and share the tips and information they receive from the program with other family members with similar concerns.

### **III. COMMUNICATION**

Strong communication skills are the foundation of ombudsman work and are vital to ombudsman success. What an ombudsman says and how he or she says it influences all aspects of ombudsman work, especially when addressing complaints. The **Overview of Key Communication Techniques** document in the appendix highlights the basic elements of communication addressed in the National Long-Term Care Ombudsman Center (NORC) Curriculum and provides other important communication techniques.

Good communication is equally important for family members. The ability to communicate well can build positive relationships with staff that translate into good care for a loved one. Strong communication skills are particularly important during problem resolution, because poor communication can result in an adversarial relationship that increases conflict instead of working together to resolve a situation.

#### ***Ombudsman Communication with Families***

##### **Speaking with families for the first time**

By the time family members contact the ombudsman, it is likely that they have been dealing with concerns related to their loved one for some time and may be frustrated. Before ombudsmen can begin processing a complaint, they need to give the family member time to tell their story and express their feelings. Ombudsmen are often the first person who really listens to what a family member is saying.

Below are some approaches that allow the ombudsman to acknowledge a family member’s feelings before seeking the information necessary to handle a complaint. These approaches may help defuse an emotionally charged situation to enable everyone to focus on the issues. They also indicate that the ombudsman has heard (listened to) the family member’s concerns and feelings.

*“It sounds like you care a lot about your aunt. It must be very upsetting to find her with food all over her face and clothes when you come in to visit.”*

*“So what I’m hearing is that you are frustrated that the nursing home administrator has not addressed the problems that you have taken to him on several occasions. Is that right?”*

*“It sounds like you have tried everything you can think of and done the best you can, but your mother is still not getting the help she needs at meals. That must be so frustrating for you. Let’s see what we can do to try to make things better.”*

**QUICK TIP:** When speaking with family members that are upset, one ombudsman begins by referring to the resident as Mr. \_\_\_\_ or Mrs. \_\_\_\_\_. As the conversation progresses, she then switches to “your mother” or “your aunt” depending on the relationship between the resident and the family member. She finds that when she makes that switch, families feel that she has really been listening and become calmer.

**Other important points to address during the first conversation with families include:**

- Discuss the role of the ombudsman (see next section), including that the ombudsman will ultimately take direction from the resident.
- Ask family members what they want the outcome to be. This can provide the ombudsman with important information about the motivation of the person. For instance, if a son’s goal is to get the administrator fired, the case is not about the resident.
- Be clear about what you can and cannot do. One ombudsman says, “We’re going to try to work through this, but sometimes there are situations that go beyond my scope. For example, if there is a nursing issue where nursing expertise is needed, that would be something the state would have to handle.”
- Explain that with the resident’s consent, you will investigate and get back to them as quickly as possible.

***Communicating the Role of the Ombudsman to Families***

Most family members have never heard of an ombudsman. When they contact the program, it is generally because someone has told them “the ombudsman can help” with a problem they have run into in the nursing home or assisted living facility. Since most families have no idea about ombudsman responsibilities and what ombudsmen can and cannot do, it is critical that ombudsmen give families a clear understanding of their role right from the very beginning. Ombudsmen should take particular care to explain that the resident is their client.

**Here are examples of what some ombudsmen say to families:**

*“The resident - your mother- is our client and we’re going to do the best we can for her.”*

*“I am a resident advocate. I am here for your mother and what she needs, and hopefully we can all work together on this.”*

*“I’m in a very unique position. I have the honor of being the trustee of your mother’s wishes. It’s important that you understand that your mother will guide me in working this out.”*

**At times a family member may say that their loved one has dementia and that it is pointless to talk with her. Responses that ombudsmen can use in this situation are:**

*“Please understand that I am duty bound to meet with the resident face-to-face even if she can’t communicate.”*

*“I will go and see her. I’ll talk with her about this and then we can see where we’ll go from there.”*

*“I understand what you are saying, but my obligation is to go and speak with her first. It’s important that I see for myself.”*

The ombudsman’s first conversation with family members must include an explanation of how the ombudsman program works and what families can expect. Ombudsmen can use the points in the **Understanding the Long-Term Care Ombudsman Program** handout (see Appendices) as guidance for this discussion. To reinforce and remind families about the points you cover, it is helpful to provide them with a copy of this handout.

### ***Helping Families Understand Why Residents May Not Want to Take Action***

Out of concern for a loved one and their desire to get a problem resolved, families may struggle with the fact that ombudsmen won’t intervene if the resident does not wish them to do so. From the family perspective, it can be difficult to comprehend why a loved one might not want to have a problem addressed. It can also be very hard to understand why the ombudsman won’t do something about a problem when a resident says no. In addition to citing the Older Americans Act requirement that the ombudsman role is to represent residents’ interests, ombudsmen can use the following points to help explain why it is important that residents have confidentiality and that ombudsmen honor their wishes.<sup>1</sup>

- Residents have very little control over their lives in the nursing home and few opportunities to make meaningful decisions. Proceeding without their consent further undermines resident control over their own lives.
- Residents often “choose their battles” regarding what concerns they voice and what they “put up with.” A family members’ concern - as important as it may be - might not be one of the “battles” that a resident wishes to wage.
- Even if they are experiencing physical or cognitive impairments, residents are adults and have the right to make decisions affecting their lives – even if those are decisions that others, including family members, don’t agree with.
- Residents’ fear of retaliation cannot be overemphasized. Even if a resident does not experience retaliation, the fear is very real. Residents have to live in the facility 24 hours a day, seven days a week and are often afraid to criticize the nursing home since they are dependent on the staff for even the most basic things in life.

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<sup>1</sup> Residents’ Rights. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center.

## Reporting back to families when a resident does not want action taken

After speaking with a resident who does not give consent to take action on a complaint, ombudsmen need to inform the family member who contacted them initially about the resident's wishes. Ombudsmen need to keep in mind that the majority of family members care deeply about their loved one and are concerned about their well-being. For that reason, simply saying that "you can't do anything because you don't have the resident's consent" is not the best response.

Instead, assure the family member that although the resident did not want ombudsman help at the moment, she will check back with the resident the next few times she is in the facility to see if the resident has changed her mind. Additionally, an ombudsman can tell the family that if she determines that other residents are having the same issue, her advocacy may also help the family member's loved one.

### Some additional things ombudsmen can do include:

- If the resident is doing well although the family member is concerned, the ombudsman could share her observations about the resident with the family member. She might say that the resident looked good and appeared content, and note that staff came by to check on the resident during her visit. At other times, if it is alright with the resident, the ombudsman might tell the family member that the resident says she is pleased with her care, likes the staff and likes her room. Both of these approaches could help reassure family members.
- An ombudsman tries to help the family member put herself in her loved one's position and imagine how she might feel if she lived in the nursing home 24 hours a day.
- The ombudsman can encourage the family member to talk about her concerns to the resident. Sometimes the resident or the family member may change their minds about taking action after a conversation.

Additional suggestions are given in the section, **"When family wishes conflict with resident wishes"** section under **"Strategies for addressing challenging situations."**

## Establishing Credibility with Families

An ombudsman's credibility directly affects their effectiveness. Ombudsmen build credibility by being knowledgeable and accurate in what they say and doing what they say they will do. When people know that an ombudsman is reliable, trustworthy, and straightforward, they are more likely to work with him or her.

An important part of establishing credibility with family members is being honest about what you can and cannot do. Only make a commitment if you are sure you can keep it. For instance, you may want to reassure a very worried family member by telling them that you will take care of the problem. However, you don't know what you may encounter with even a simple problem. Instead of promising to solve the problem, let the family member know that you will do your best to help find a solution that works for everybody.

**Example:**

One ombudsman says, “We’re going to try to fix this and we’ll give it our best shot.”

To establish credibility ombudsmen need to be direct and open with families. This includes informing them about the risks and benefits of any particular action that may be taken. Your actions on behalf of a resident may lead to results that you had not intended and that may not be desirable. One ombudsman calls this the “rule of unintended consequences.” Below is an example of how unintended consequences can occur.

A resident who wanted to transfer from one nursing home to another requested assistance from an ombudsman. The ombudsman helped to ensure that the steps were taken for such a transfer. However, in this particular state this type of transfer triggers the need to conduct a new pre-admission screening (PAS). Unexpectedly, the PAS results indicated that the resident was no longer eligible for Nursing Home Medicaid Level of Care because she did not have the five deficits required for medical eligibility. Not only did this prohibit the resident from transferring to another facility, it also resulted in her losing her Medicaid reimbursement for the facility in which she was residing.

You, the ombudsman, should do your best to think through and anticipate what some of those consequences may be and share them with family members before proceeding. In addition, you need to stress that there may be other consequences that you can’t foresee at the moment. Being upfront with families allows them to know from the start what they may be facing and permits them to make an informed decision about whether and how to proceed.

Misperceptions about your role or intent also affect your credibility as an ombudsman. Your actions send a message about your role and your work, but that message may not be the one you want to communicate.

**Consider the following situation described in the Institute of Medicine study of the ombudsman program:**

An ombudsman schedules a meeting between a nursing facility and a family lodging a complaint about the care of their mother. The ombudsman ... has received other complaints about the facility.... The ombudsman arrives at the facility before the family and proceeds to the administrator’s office to discuss another case not yet resolved. The family arrives and observes that the ombudsman is already in the administrator’s office. The family may question ... the loyalty of the ombudsman and assume that the ombudsman has other relationships or interests that compromise the resident’s interest.<sup>2</sup>

**Examples of other possible situations where your actions could create a misperception of conflict of interest include:**

- You live in a small town and run into the administrator of the town’s only nursing home while you are shopping at the grocery store. You have a friendly chat with her.

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<sup>2</sup> Institute of Medicine. *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. 1995. p. 114.

- You have set up a care plan conference as a way to try to resolve a concern raised by a resident's daughter. You arrive before the family and the nursing home staff invites you into the conference room, where you sit and talk with staff until the daughter gets there.
- The nursing home contacts you and asks that you attend a care plan meeting concerning the care of a resident. The nursing home tells you that the resident's two sons will attend the meeting. You go to the meeting without talking to the resident or the two sons.

Your credibility - one of the ombudsman's greatest strengths – can be affected when family members observe actions that can lead them to believe that you are “on the facility's side.” To avoid or minimize situations where misperceptions might arise, ombudsmen can take the following steps:

- Explain to family members early on that to investigate complaints and work to resolve them requires you to speak with the administrator and other nursing home staff. As a result they may see you talking with facility personnel.
- Plan to meet with family members prior to the start of a care plan conference. You could meet in front of the facility, in the resident's room or in the lobby. Walk into the care plan meeting with the family. Sit next to the resident, if possible, or the family members.
- When asked to attend a care plan conference by the facility, inform staff that you will not participate unless the resident and family members have given you permission. Contact the resident and the family to speak with them about the situation and whether they wish you to be present.
- When you encounter facility administration and staff in the community, interact with them as you would in the facility - be professional, courteous and polite, but not overly friendly.
- If you have gone to school with a staff person or have some other connection with a facility employee, disclose that to families right from the start so they don't think you were hiding something if they learn about it later on.
- If you receive a complaint or request for ombudsman services from the facility, tell them they should encourage the resident or family to call you directly if they would like you involved.

As noted by the Institute of Medicine study, perception by clients needs to be “an important and ongoing consideration in an effective ombudsman program.”

#### **IV. KNOWLEDGE IS POWER: RESOURCES FOR FAMILY MEMBERS**

Educating family members is an important role of ombudsmen. Many families are anxious about placing the care of a dependent loved one in the hands of others. Providing families with information could reduce their anxiety once they understand that their loved one has rights and is protected by laws and regulations. Knowledge about the long-term care system also provides family members with a foundation for working to ensure their loved one receives the best possible care.



The **Resources for Family Members** document in the appendix includes resources that ombudsmen can use to educate families about nursing facility requirements, assisted living, resident rights, family rights and decision-making, family councils and advocating for quality care.

## **V. EFFECTIVE COMMUNICATION AND SELF-ADVOCACY SKILLS TO EMPOWER FAMILY MEMBERS**

### ***Effective Communication***

As noted earlier, strong communication skills are important for families as well as for ombudsmen. Effective communication allows families to work cooperatively with facility staff to ensure residents receive quality care. As they work with a family member, ombudsmen can model ways to communicate with administration and staff and share information on communication techniques.

Resources ombudsmen can share with family members regarding effective communication and self-advocacy are listed in the **Resources for Family Members** document in the appendices.

### ***Barriers to Self-Advocacy***

While some family members may not hesitate to advocate on their own when a problem arises, others may be reluctant to speak up on behalf of a loved one.

There are a number of reasons why families, like residents, may be unwilling or afraid to voice concerns. Many family members fear retaliation against their loved one. This fear is prevalent and sadly, in too many cases, it is valid. Family members may also be concerned the facility might retaliate against them. This is another valid fear. Families who complain about a loved one's care may find facility staff attempting to limit or restrict their visits. Family members have even reported that the police have been called in during their visits.

In addition to fears of retaliation, family members may not have enough knowledge about how the facility operates and may not know the best way to approach problem-solving. As a result they may take their problem to a staff person who has no ability or authority to address the issue. When nothing happens, family members may feel discouraged and hopeless. At other times, families may know exactly the right person to take the problem to, but after bringing problems up repeatedly and getting no results, families may conclude that self-advocacy is pointless.

Finally, family members may fear that once the facility staff has labeled them as "complainers" or "guilty children" their credibility will decrease and their concerns will be discounted.<sup>3</sup>

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<sup>3</sup> The Problem-Solving Process: Investigation, p.15. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center.

**QUICK TIP:** Here are a couple of ways ombudsmen can respond when family members are reluctant to voice their concerns due to fear of retaliation.

*“While we will do what we can to prevent it, I can’t guarantee that there won’t be retaliation. However, I am sure that nothing will change if you don’t speak up.”*

*“Federal nursing home regulations state the resident or resident’s legal representative has the right to voice grievances without the fear of reprisal and you can file a complaint if you or your loved one experience retaliation.”*

Encourage family members to document all aspects regarding their complaint (e.g. examples supporting their complaint, when they addressed the complaint with staff and how staff responded) in order to have a timeline of events if they need to file a complaint due to retaliation.

### **Teaching Problem Solving Skills**

Helping family members to advocate on their own, and if necessary, to overcome barriers to self-advocacy, is at the heart of ombudsman work. As stated in the NORC Curriculum, “As an ombudsman, empowerment needs to be your primary way of relating to individuals.... You are always seeking to enable others to speak up on their own behalf....”<sup>4</sup> Empowering family members is important because it opens up communication between the family and the staff improving the ability to solve problems. Furthermore, when family members act on their own, their relationship with facility staff is more likely to be preserved, making it easier for families and staff to work together for the resident.

**REMINDER:** Prior to discussing problem-solving skills with families, ombudsmen should encourage family members to speak with their loved one to see if he or she shares their concern and whether the resident wants anything to be done about the matter. Ombudsmen should urge families to honor the resident’s wishes and/or preferences. While ombudsmen can’t ensure that families will do so, they can explain why consulting with and being guided by their loved one is important.

This section outlines one approach to assisting families to solve problems on their own. As ombudsmen know, advocacy is basically problem-solving. Just as new ombudsmen learn the steps to go through to systematically analyze and address a complaint, families may benefit from using a very similar process.<sup>5</sup> The table below outlines a problem-solving process for families.

<sup>4</sup> Residents’ Rights, p. 6. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center.

<sup>5</sup> The Problem-Solving Process: Investigation, p. 9. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center.

## The Problem-Solving Process for Families

### Stage I: Defining the Problem

<b>Step 1: Identify the problem</b>	What exactly is the problem? Describe the problem with as much specific detail as possible.
<b>Step 2: Identify supporting information.</b>	What information do you have about the problem? Information can come from observation, discussion with a loved one or staff, documents, etc.
<b>Step 3: Write a statement of the problem with supporting information.</b>	Use objective, factual language (See the <b>Documentation Tips for Family Members</b> resource in the appendices) when writing your statement and include information/evidence that supports your statement.
<b>Step 4: (Optional) Identify if there are any laws or regulations that address the problem.</b>	While you should voice any concern that you believe is a problem, it can strengthen your case and increase your confidence if you know what (if any) regulations are applicable. You can look up state and federal nursing facility regulations and state assisted living regulations at the following website or consult the local ombudsman <a href="http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html">http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html</a> .

### Stage II: Analysis and Planning

<b>Step 5: Determine your goal</b>	What does (or would) your loved one want to happen? What is an acceptable resolution? What outcome will benefit your loved one? Make sure the goal is realistic and benefits your loved one. For example, instead of setting a goal to get the charge nurse fired, determine what needs to be addressed and resolved regarding the charge nurse's impact on your loved one's care.
<b>Step 6: Assess what has already been done</b>	Think about the steps that you have already taken to resolve this problem. Whom did you talk to, when was the conversation, what did they say? What, if anything, happened after speaking with them?
<b>Step 7: Consider possible approaches</b>	Identify what action you could take to try to solve the problem at this point. Examples of approaches include: <ul style="list-style-type: none"> <li>• Find out if there is a designated person on staff to handle complaints and then speak with that person</li> <li>• Speak with the charge nurse</li> <li>• Speak with the Director of Nursing</li> <li>• Speak with the Administrator</li> <li>• Discuss the problem during a care plan conference</li> <li>• Take the problem to the family council</li> </ul>
<b>Step 8: Identify the pros and cons of each possible approach you came up with in Step 7.</b>	Think through the "pros" and "cons" of the approaches you identified.
<b>Step 9: Choose an</b>	After weighing the pros and cons, decide on the approach you think would be best

<b>approach</b>	given the situation and what you are comfortable doing.
<b>Step 10: Act!!</b>	Take the action you decided on in Step 9. Follow up any discussion you had with facility administration or staff by sending a note summarizing the discussion and including any specific steps the nursing home stated it would take.
<b>Step 11: Evaluate the outcome</b>	<p>What is the result of your action? Is the problem resolved? Partially resolved? Not resolved? If the problem is resolved, thank the facility administration and staff.</p> <p>If the problem is only partially resolved or not resolved at all:</p> <p>a) Repeat Steps 7-11  <i>Possible approaches at this point include:</i> <ul style="list-style-type: none"> <li>• Meeting with the administrator</li> <li>• Writing a letter to the administrator and copying (“cc”) the corporate office and the ombudsman</li> <li>• Writing to and/or meeting with a regional manager or someone from corporate office (for-profit facilities)</li> <li>• Writing to or meeting with the facility’s board of directors (non-profit facilities)</li> <li>• Taking the issue to the family council or forming a council if one does not exist</li> </ul> </p> <p>b) Identify where you could turn for assistance  <i>Examples include:</i> <ul style="list-style-type: none"> <li>• The ombudsman program (to find a local ombudsman and other state agencies visit <a href="http://www.ltombudsman.org">http://www.ltombudsman.org</a>)</li> <li>• The state survey agency to file a complaint (to find your state survey agency and other state agencies visit <a href="http://www.ltombudsman.org">http://www.ltombudsman.org</a>)</li> <li>• A citizen advocacy group (CAG) if one exists in your state. (To find information regarding CAGs and locate a CAG , visit the Consumer Voice CAG webpage: <a href="http://www.theconsumervoice.org/advocate/advocacy-group-center">http://www.theconsumervoice.org/advocate/advocacy-group-center</a>)</li> </ul> </p>

Ombudsmen can consult the **Teaching Self-Advocacy to Families: Tips for Ombudsmen** guide for step-by-step tips for how to coach family members in the problem-solving process and how to apply the process to their problem. You can access the guide in the appendices.

When ombudsmen are contacted by a family member about a problem, they first need to evaluate whether the problem lends itself to self-advocacy. If so, and if the family is willing and able to address the problem themselves, ombudsmen can send family members the following resources (all of the resources below are available in the appendices):

- **The Problem-Solving Process for Families:** This table (above) is available as a handout in the appendices.
- **Problem-Solving Worksheet for Families:** This worksheet presents the contents of the table in a worksheet format so that family members can write out their responses.

- **Problem-Solving Worksheet for Families- EXAMPLE:** This handout gives families a sample problem and then demonstrates how to work through the problem-solving process by providing completed responses.
- **Documentation Tips for Family Members:** This handout helps families prepare a written statement or description about a problem in a way that is factual and objective.
- **Strategies for Addressing Concerns in Long-Term Care Facilities:** This handout is a concise outline of steps that family members can take to resolve a problem.
- **Recommendations for Meeting with Facility Administration and Staff:** This handout provides quick tips about preparing for and participating in meetings with facility staff.

A list of additional resources regarding problem-solving is in the **Resources for Family Members** document in the appendices.

#### **Ombudsmen can:**

- Encourage family members to call back if:
  - they have any questions about the materials;
  - if they need assistance in applying the problem-solving process to their concern; or
  - if they advocate on their own and are not successful; or
- Instruct families in resolving problems on their own using, **Teaching Self- Advocacy to Families: Tips for Ombudsmen**. Instruction can take place over the phone or in person.

**QUICK TIP:** Consider creating a **Family Advocacy Toolkit** to give to family members. Include the handouts listed above and a copy of **Nursing Homes: Getting Good Care There**.

## **VI. STRATEGIES FOR ADDRESSING CHALLENGING SITUATIONS**

### ***Stressors experienced by families***

As noted earlier, by the time many families connect with an ombudsman, they may be extremely frustrated. Here is what may have preceded their call to you:

- They have taken the same problem to staff repeatedly and were told it would be fixed, but it hasn't been- and are then told by staff that they have an "attitude."
- They feel that every time they walk into the nursing home, there will be some problem they will have to address instead of simply visiting with their loved one.
- They have found their loved one wet with urine, soiled with feces, unkempt, drooling and slumped over in a wheelchair, in pain – or all of the above - on multiple occasions.

- They have determined that they have to be in the nursing home all the time or else their loved one won't get even the most basic care and attention she needs.
- They feel that their complaints have been discounted, ignored, and minimized so often by the staff that they have to get evidence - like hanging onto and showing staff soiled clothing - to prove there's a problem.

Consequently, the family members you work with may feel stressed and overwhelmed. Ombudsmen need to remind themselves that when the well-being and safety of someone you love very much is at stake, intense feelings are aroused that can sometimes result in challenging situations.

### ***Tips for addressing challenging situations***

Most families establish a working relationship with facility staff and are able to address problems on their own when they arise. These are the family members that don't contact you. Other families simply need you to provide information, guidance and support or to intervene once or occasionally to resolve concerns.

However, there are times when ombudsmen may find themselves addressing some complicated and challenging situations with family members. Because each situation and each family are different, there are no "one size fits all" solutions. Nevertheless, here are some "tips" from experienced ombudsmen about approaches that may be helpful in certain situations.

### **Resistance**

#### Family resistance to working with a particular ombudsman

*Situation: A family member insists that a different ombudsman be assigned to work with her.*

Possible approaches include the following:

- Try to determine the reason for the resistance as that will influence how an ombudsman responds. For example:
  - If a family is resistant because they believe the ombudsman is on the "facility's side," see if you can determine what led to that belief. As noted earlier, this impression sometimes arises when family members observe the ombudsman speaking with the administrator or staff. Have a conversation to address the concerns of the family. For example, your response might be to explain that ombudsman can't resolve problems without speaking with facility administration and staff.
  - If a family member does not want to work with an ombudsman because they feel the ombudsman is not handling the case well or appropriately, the state ombudsman or regional ombudsman/ombudsman coordinator can ask the family to explain what has been done to-date, ask the ombudsman handling the complaint to do the same thing, and then assess the situation. If the state ombudsman or regional ombudsman/ombudsman coordinator determines that the ombudsman has handled the complaint well, they can

provide that feedback to the family member. If on the other hand the state ombudsman or regional ombudsman/ombudsman coordinator believes that the ombudsman skills are not at the level they should be, the state ombudsman or regional ombudsman/ombudsman coordinator can use that as a training opportunity for the ombudsman. The state ombudsman or regional ombudsman/ombudsman coordinator can tell the family member that they will be providing technical assistance and consultation to the ombudsman as the ombudsman works on the complaint.

- Ask another ombudsman to accompany you. For example, ombudsmen that use this approach have found that having the second ombudsman listen and respond to the family can make a difference. The second ombudsman may say exactly the same thing as the first ombudsman, but because the words are coming from another person, the family member may hear it differently. Such an approach may demonstrate to the family member that changing ombudsmen does not change the way in which a complaint is handled and can increase family confidence in the first ombudsman.
- Request that another ombudsman handle the case.
- Find a way to help the ombudsman and family work together. For example:
  - The ombudsman can request assistance from another ombudsman. For example, a local ombudsman could meet with the family member and volunteer ombudsman to discuss the case.
  - The ombudsman could tell the family member that they will consult their supervising ombudsman regarding the case. This approach gives the family the assurance that the ombudsman's actions have been reviewed by their supervising ombudsman (e.g. a local ombudsman could consult with the state ombudsman).

**QUICK TIP:** State Ombudsmen should make sure they have policies and procedures in place in the event that a family member says they cannot work with a specific ombudsman.

#### Ombudsman resistance to working with a particular family

*Situation: The local ombudsman insists she can't work with a family or individual family member.*

Possible approaches include the following:

- Assess the situation to determine what is causing the problem. The State Ombudsman or regional ombudsman should conduct this assessment. In some cases, providing additional training or guidance to the ombudsman may be what is needed.
- Ask another ombudsman to handle the case. For example, in one state a family member misrepresented what a local ombudsman said to the nursing home. The misrepresentation was damaging to the ombudsman and impacted his credibility and ability to advocate in the nursing

home. Therefore, the ombudsman did not want to work with this family. To address this problem, the ombudsman supervisor took over the case.

- Team up. Another ombudsman could partner with the local ombudsman and share responsibilities. For example, one ombudsman could handle correspondence with the family member and the other ombudsman could address other aspects of the case.
- Create a process for helping the ombudsman and family to work together. This approach is similar to the last point in the previous section. Such a process might involve requesting assistance from another ombudsman to intervene and try to move the case forward. Another option might call for the ombudsman to consult with their supervising ombudsman regarding the case. Consultation might reassure the ombudsman since her supervising ombudsman has reviewed her actions regarding the case (e.g. a volunteer ombudsman consults her local ombudsman).

**QUICK TIP:** State Ombudsman Programs should have policies and procedures in place for addressing this situation.

#### **When family wishes conflict with resident wishes**

*Situation: A family member has a concern about care, but the resident either does not share the concern or does not want anything done about it.*

As a general rule of thumb, since ombudsmen are resident-directed they must be guided by what the resident wishes. If the resident is able to communicate what she wants and does not want the complaint to be pursued, the ombudsman must honor her request.

**REMINDER:** Although a resident may not provide consent to pursue a complaint there are other actions ombudsmen can take that will both honor the resident's confidentiality and work to ensure the resident is receiving quality care and is protected from harm.

Residents are often reluctant to complain due to fear of retaliation; however, when an ombudsman receives a complaint about care, or allegations of abuse, neglect or exploitation the ombudsman should consider approaches to ensure the safety of the resident without compromising his/her confidentiality.

In addition to the information below regarding possible actions, please review the **"Reporting back to families when a resident does not want action taken"** and **"Family members suspected of exploiting or abusing a resident"** sections.

However, if the resident is concerned about the issue, but does not want the ombudsman to take action, the ombudsman should explore the reasons for her reluctance. In situations where reluctance is due to fear of retaliation, the ombudsman should explain to the resident her rights, that the ombudsman will stand by her throughout the process and not take any steps without the resident's



express permission. Should the resident still not want to have action taken on a concern, the ombudsman should follow the resident's wishes.

In cases where the resident does not want anything to be done, the ombudsman should explain to the family that they are obligated to honor the resident's directions. Explaining this to family members is easier when ombudsmen effectively communicate that LTCO actions are resident-led during their initial conversation with the families (see the **"Communicating the role of the ombudsman to families"** section). Additionally, the ombudsman should try to help the family member understand in general why residents sometimes don't choose to take action and why it is important to honor residents' wishes. The points identified in the section, "Helping families understand why residents may not want to take action" may help ombudsmen in providing this explanation. With the resident's permission, the ombudsman can also share the specific reasons why the resident does not want to proceed.

It is important to remember that the vast majority of families care deeply for the resident and are very concerned about her well-being. As a result, simply saying "I can't work with you" can leave families anxious and worried. Instead, here are some approaches an ombudsman might try:

- Share positive observations about the resident with the family member. For example:
  - After hearing a daughter's concern that her mother was poorly groomed and learning from the resident that she didn't want the ombudsman to do anything, the ombudsman reported the resident's response back to the daughter. However, the ombudsman also shared with the family member that she had observed that her mother looked neat and well-groomed and that staff appeared very attentive. The ombudsman added that she could tell that the daughter cared a great deal about her mother and that she hoped the daughter would now feel better about her mother's care.
- Tell the family that you will see if you observe the problem yourself or if any other residents are experiencing the same problem (see below).
- Inform the family member that you will check back with the resident again in a few weeks to see if she has changed her mind.
- See if there are other residents with the same issue who are willing to pursue it to resolution. By resolving the issue for others, you might be able to resolve it for the resident who does not want you to proceed on her behalf.<sup>6</sup>
- Inform families about what they can do to take action to achieve the outcome the resident would want (e.g. facilitate a conversation between the resident and family member).
- Encourage families to take their concern to the family council. If there is not an existing family council, encourage them to form one and provide them with resources and information about family councils.

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<sup>6</sup> The Problem-Solving Process: Investigation. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center. 2006.

- Pursue a broader investigation if you believe there is a problem with care in the facility, taking care not to do anything that would reveal the resident's identity.<sup>7</sup>
- Pursue an ombudsman-generated complaint if you observe the problem yourself.
- Facilitate a conversation between the resident and the family member. Encourage the family member to speak with the resident and explain their concern and why they feel it is important to take action. Speak with the resident too, and support her in communicating with her family member and have a discussion about resident rights.
- Present options. The ombudsman can ask the family member what it would take for him/her to feel better about a loved one's care or situation and explain that to arrive at that point the family member needs to be willing to compromise. Then, if the resident says no to one option, the ombudsman can present other possible approaches. For example, a local ombudsman who uses this strategy notes that when given some choices, the resident will often find one that she is willing to try. The ombudsman then goes back to the family member and tells her that her mother said no to the original option, but has agreed to a different one. Although this may not have been the family member's preference, the ombudsman finds that family members will usually agree to go in that direction instead in order to achieve some resolution to the problem.

### **Family member won't let go of problem(s) from the past**

*Situation: A family member is still upset about an incident regarding the care of his mother that occurred in the past and was discussed with the staff at the time of the incident. Reminders of this incident are triggered each time he has a concern about the care of his mother. He brings up the past incident every time he speaks with facility staff (even if the past incident isn't related to his current concern). When he refers back to the prior incident it upsets the staff – many of whom were not working at the facility at the time of the prior incident. He requests your assistance in addressing his current concerns about his mother's care.*

#### If the ombudsman is working with a family member for the first time:

- Start by validating what the family member is saying. An example of this might be: "It sounds like you went through a terrible experience. I'm so sorry that happened."
- Ask the family member to tell you the complete story. While you may feel that you don't have time to listen to a problem from the past, families need to tell their story because it has clearly affected them significantly. It's best to provide them with the opportunity to do so early on. Hearing the story also helps you better understand the dynamics between the family member and nursing home staff and can provide insight into how to move forward with the current problem.

#### If the family member continues to bring up the past issue after having shared the story with you:

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<sup>7</sup> Ibid, p. 7

- Acknowledge what family members say they have experienced in the past and help to re-establish trust between the family member and the nursing home. For example, a local ombudsman says to families:

“I understand the issues you’ve had and why you don’t have much trust in what nursing home staff tells you right now. We need to work to build that trust from today on.” She then asks the family for a list of their concerns that, if resolved, would rebuild their faith in the nursing home. The ombudsman usually requests that the family select their top two concerns and then helps to address those problems. After resolving the issues with the nursing home and establishing a point of contact at the facility for the family to turn to, she tells family members to notify her immediately if they call the contact person and don’t get a response. The ombudsman has observed this approach gives families more confidence and improves communication between the family members and nursing home staff.

- Ask them to document every detail about the experience and give a copy to you. Thank them and say that you now have everything you need to know about the incident and will refer to it if you ever need that information. Assure them that if the issue comes up as you are working on the current problem you will address it. .
- Explain that referring to the previous incident detracts focus from the current issue and interferes with attempts to solve their present concern.
- Inform the family member that in order to best assist them with their concern, you will redirect the conversation back to the current situation if the past incident is mentioned. For example, if a family member brings up the previous incident again, you could say, “I’m so sorry that happened. Now let’s go back to your present concern.”
- Be a broken record. Repeat “I’m so sorry that happened. Now let’s go back to your present concern” as many times as necessary. Hold firm.

**If a family member has lost trust in the facility staff and has unresolved concerns about their loved one’s care, can an LTCO propose relocation as an option?**

In order to avoid the appearance of conflict of interest or that the LTCO is not supportive of the residents’ right to advocate for their highest practicable quality of care and life in their current home, it should be a rare occasion that the LTCO mention the option of relocation.

Prior to discussing the possibility of relocation all other means of complaint resolution and problem solving strategies should be exhausted.

If facility staff suggest the option to move to another facility when responding to a complaint, in addition to not working with the family member and resident to resolve their concerns, this approach could be, or appear to be, retaliation or intimidation. Therefore, if a LTCO were to mention relocation as an option due to the family member’s lack of trust in the current facility, the family member may think the LTCO is dismissing their concerns and is “on the facility’s side.”

If the family member suggests the possibility of moving their loved one to another facility, the LTCO should share the possible positive and negative outcomes of relocation for the resident (e.g. the relocation process may be difficult for their loved one, relocation options may be limited).

### **Family member monopolizes the ombudsman's time**

*Situation: A family member calls frequently. The calls take so much time that the ombudsman is not able to give other cases the attention they need.*

In this situation, the key is to set boundaries. Possible approaches include the following:

- Set a regular time to speak with the family by phone. This approach guarantees the family member has the opportunity to communicate any new information or concerns and that s/he feels heard. This strategy also allows the ombudsman to control the amount of time spent on this one case. For instance the scheduled phone time could be from 2:00 – 2:30 pm every two weeks. Make sure to end at exactly the time you set. To end the conversation, you can say, “Thank you for sharing this information with me. I need to move on to my next appointment, so I’ll speak with you again in two weeks.”
- Request that the family member submit information in writing. Therefore, the family member can provide you with detailed information in a manner that is time efficient. You can respond by email, in writing or schedule a time to talk with the family. Make sure any scheduled time includes an ending time and hold firmly to that time.
- Suggest that the family member join or create a Family Council to see if other family members have similar concerns.

### **Family members suspected of exploiting or abusing a resident**

*Situation: You suspect that a family member is abusing or financially exploiting a resident.*

Ombudsmen should handle situations involving resident exploitation/abuse by a family member using the same basic ombudsman procedures they employ with all complaints and follow the three stages of problem-solving presented in the NORC curriculum.<sup>8</sup> However, exploitation/abuse cases differ from other complaints in that most states require abuse to be reported. These reporting requirements conflict with strict ombudsman confidentiality provisions under the Older Americans Act that prohibit ombudsmen from revealing the identity of the resident without resident consent.

Below are some suggested approaches for handling abuse/exploitation situations and addressing reporting requirements in a way that does not violate resident confidentiality. These approaches have been adapted from the Georgia Long-Term Care Ombudsman Program Policies and Procedures Manual.

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<sup>8</sup> “The Problem-Solving Process: Investigation. NORC Curriculum. Written by Sara Hunt for the National Long-Term Care Ombudsman Resource Center.

IF the resident	THEN the LTCO shall...
Gives permission to the LTCO to make the report	Report the suspected abuse or gross neglect to the appropriate agency, and, when appropriate, to law enforcement
i) Does not give permission to a LTCO to make the report; <i>and</i> ii) The complainant is a long-term care service provider, facility staff person, or other mandatory reporter	Inform the complainant of his or her duty to report the alleged abuse to the appropriate agency.
i) Does not give permission to a LTCO to make the report; <i>and</i> ii) Acknowledges having been abused	i) Determine: 1) Whether other residents have experienced similar circumstances; <i>and</i> 2) Whether any other resident wishes the LTCO to take any action on his or her behalf; <i>and</i> ii) Make repeat visits to the resident who alleged abuse or gross neglect in order to encourage the resident to permit the LTCO to report the suspected abuse or gross neglect
Is unable to communicate his or her wishes	Refer the suspected abuse or gross neglect to the appropriate agency under ombudsman authority to protect the resident's right to be free from abuse or gross neglect
Does not make the complaint (e.g. the LTCO receives a complaint of suspected abuse or neglect from a complainant other than the resident)	i) Advise the complainant to report the suspected abuse or neglect to the appropriate agency and provide information to assist the complainant in making the report; <i>and</i> ii) Visit the resident and follow complaint investigation steps
i) Does not make the complaint; <i>and</i> ii) The LTCO personally witnesses abuse of a resident	i) Report the alleged abuse witnessed by the LTCO to the appropriate agency; ii) File an ombudsman-generated complaint
Requests the LTCO to not make a report of abuse personally witnessed by the LTCO	i) Determine: 1) Whether other residents have experienced similar circumstances; <i>and</i> 2) Whether any other resident wishes the LTCO to take any action on his or her behalf; <i>and</i> ii) Make repeat visits to the resident who was the victim of abuse observed by the LTCO in order to encourage the resident to permit the LTCO to report the alleged abuse or gross neglect.

Frequently, facilities call the ombudsman in cases of alleged exploitation/abuse involving a family member.

**In addition to reminding facility staff that they are mandatory reporters of abuse under law and need to report the suspected abuse to the appropriate agency, the ombudsman may suggest that the facility:**

- Supervise visits until the situation is resolved in cases of abuse.
- Send a letter to the family stating that the family's actions could be considered abuse/exploitation under law; the situation is being monitored; and there are agencies charged with investigation of exploitation/abuse and the facility have filed complaints with the appropriate agency.
- Bring someone with expertise in from the community in cases of domestic abuse to work with the resident, the family and staff.

Addressing allegations of financial exploitation:

- Follow your state LTCOP policies and procedures regarding allegations of abuse (e.g. if you are a local LTCO consult your state LTCO).
- Advocate for finding an alternate representative payee for the resident.
- Consult the National Long-Term Care Ombudsman Resource Center (NORC) training call, "Actions Ombudsmen Can Take to Prevent Discharge Notices Due to Non-Payment" for ideas <http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/2009-Actions-Ombudsmen-Can-Take-to-Prevent-Discharge.pdf> and additional resources regarding responding to elder abuse (including financial exploitation) <http://www.ltombudsman.org/issues/elder-abuse-elder-justice> (additional resources listed in the Appendices).

**Family conflicts**

*Situation: Families may at times end up fighting among themselves. They may disagree about what should be done for the resident or may even take actions against each other, like one family attempting to block visitation by other family members.*

When there is conflict over care

**If the resident wishes action to be taken, possible approaches include the following:**

***Request a care plan meeting***

A care plan meeting that includes the resident, if possible, and all family members (some may participate by phone if necessary) can be a way to resolve conflicts about care. A care plan meeting provides everyone with an opportunity to receive the same information, at the same time.

Prior to the care plan meeting, the ombudsman should make sure the resident has agreed to the ombudsman's participation in the meeting, ensure the family members have been informed that the ombudsman will participate in the meeting request and that all participants understand the role of the ombudsman.

During the meeting, if conflict arises between family members, turn to the resident and ask her what she wants. If the resident is not present, ask, “What would your mom want? What would work best for her?” Keep bringing the conversation back to the resident.

Document what was agreed to during the meeting and send everyone a copy.

### ***Hold a family meeting***

With the resident’s permission, consider asking the facility social worker or someone else the resident chooses (e.g. family friend, clergyman) to act as a facilitator for a family meeting and you, as the ombudsman, can participate as the resident advocate. If necessary, the family may want to consult a mediator or hire a mediator for the meeting.

If you facilitate the meeting, consider the following tips:

- With resident permission, ask each family member to attend a meeting. Inform them upfront that the meeting may last a couple of hours.
- Encourage the resident to attend the meeting. If the resident chooses to join the meeting, ask her if you may sit next to her in order to provide her with support during the meeting.
- Conduct the meeting in a comfortable, private room.
- Open the meeting by explaining who you are and the role of the ombudsman. Explain the reason for the meeting, review “housekeeping” matters (e.g. location of restroom, how long the meeting will go), and discuss ground rules for effective communication (e.g. listen to each other).
- Explain that one of the goals of the meeting is to get everyone “on the same team” in support of the resident, regarding her care and quality of life.
- Ask each person, including the resident, to say who they are, why they are there, and share their concerns.
- Encourage everyone to use “I-Statements” and to say “I need” instead of “You should.”
- Document the concerns shared during the meeting.
- Ask the resident for assistance in assigning priority to the concerns and discuss them with the family members.
- Facilitate a discussion about the top priority and discuss the other issues depending on the amount of time available (you may need more than one meeting).
- Strive for consensus and compromise to reach an agreed-upon solution for each issue.
- Document the decisions and agreements that were made during the meeting.

### Example:

*A local ombudsman held a meeting attended by a resident and her five adult children. The adult children had not been in the same room together for ten years. The ombudsman explained that the goal was to get them to communicate and address their mother's needs as a team. The meeting was so successful the family has elected a chair and now holds a meeting every three weeks at their mother's nursing home - with one of them bringing in a meal to share each time.*

### When families take action against each other

Unfortunately, there are times when contention within a family is so great that using the resident becomes a way to attack each other. One of the most common scenarios that ombudsmen may encounter is when one family member bars another family member from visiting the resident.

To address this situation, the first step is to talk with the resident and determine her wishes. If she does not object to the ban and does not want action to be taken, the ombudsman should proceed no further. Frequently, however, the resident does want to see this relative. In that case, if the resident lives in a nursing home the ombudsman should advocate that under federal nursing home regulations, the resident has the right to visit with any family member she wishes and that only the resident can restrict who visits her.

The family member who seeks to bar a sibling or other relative from visiting may argue that they hold power of attorney or are the resident's guardian and therefore have the authority to impose such restrictions. Let's consider each of these scenarios separately.

- **First, if the family member is an agent under a power of attorney, ask what kind of power of attorney it is.** If it is a financial power of attorney, the agent would have no say in personal and medical decision-making. If it is a health care power of attorney, remember that even though the resident has appointed an agent to make decisions when she cannot, the resident directs her own care until she is no longer able to do so. Moreover, perhaps the resident still has the capacity to revoke the document. In effect, by voicing her desire to see the barred relative, the resident revokes or overrides the authority given in the document. It is important to understand that the authority in an advance directive or power of attorney is "given" not "taken" -- it is to be used as a way to voice the resident's wishes when he or she cannot. Finally, of course make sure the agent is aware of federal and state residents' rights, and that the appointment of an agent does not remove such rights. Ultimately, if the agent still insists on restricting certain visitors, mediation may be useful, or the family member who is barred from visitation may need to consider other options, such as seek guardianship or otherwise challenge the bar in court.
- **If the family member is a guardian, the situation is more complicated because a court is involved.** First, make sure the person really is a court-appointed guardian, and not merely a caregiver using the term "guardian" informally. Second, not all guardians have authority over personal decisions. Try to find out if the guardian has authority over property, person or both, or if there are any limitations in the court order. Third, check -- or ask a willing attorney to check -- state law concerning a guardian's authority to restrict visitation. Fourth, make sure the guardian is aware of federal and state residents' rights, and that the appointment of a guardian does not remove such rights unless harm to the resident is involved. Fifth, make sure the



guardian is aware of the National Guardianship Association *Standards of Practice* language that says the guardian “shall encourage and support the person in maintaining contact with family and friends, as defined by the person, unless it will substantially harm the person” (Standard #4). If the guardian still insists on the restriction, arguing that visits would harm the resident, you may need to file a complaint in court.

If the resident is able to communicate a desire to visit with the family member whom the guardian or power of attorney desires to bar, the ombudsman should advocate for the resident’s wishes even if she has limited decision-making capacity. If the resident cannot express what she would like, the ombudsman should work with others to try to determine what the resident’s wishes would have been regarding visits from this family member. The ombudsman should then advocate for her wishes to be respected.

The ombudsman will need to proceed differently if the reason given for visit restriction is suspected abuse of the resident. Under these circumstances, the ombudsman should urge the family member pursuing the visitation ban to share their concerns with the facility and report the alleged abuse to the appropriate agency and follow the steps outlined in the section “Family members who are exploiting or abusing a resident.” Pending resolution of this situation, the ombudsman could ask the resident if she wants to have supervised visits with the family member.

#### **Family member designated as the resident’s agent in a Power of Attorney (POA) document for a resident whose decision-making capacity is unclear**

*Situation: A family member who is the resident’s agent per a health care power of attorney document contacts the ombudsman about a care concern. The ombudsman starts by speaking with the resident to see if she shares her relative’s concern and if she would like the ombudsman to take any action. However, after this conversation with the resident, the ombudsman is uncertain about the resident’s decision-making capacity and her wishes. The ombudsman is unclear about whether to be guided by the resident or the family member.*

As the number of residents with dementia grows in long-term care facilities, this scenario will occur more frequently.

Below are some steps that an ombudsman can take in this situation:

- Ask the family member and staff if there is a time of day that the resident is most oriented. Visit the resident at that time and talk with her again about her relative’s concern and whether she would like anything to be done. In addition, visit and talk with the resident several times on different days, varying the time of your visit. Compare the responses you receive. This kind of support will enhance the resident’s ability to make decisions.
- If the resident gives a consistent response over time, the ombudsman should accept that as an indication of the resident’s wishes and advocate for what the resident wants. Even though the family member may hold a health care power of attorney, the resident still has the authority to direct her own care until she is no longer capable of decision-making.
- If the resident’s wishes are contrary to what the family member wants, remind them of your earlier conversation with them about your serving as an advocate for the resident (see the

**“Communicating the role of the ombudsman to families”** section). Refer back to the section, **“When family wishes conflict with resident wishes”** for additional suggestions.

- If the resident is not able to provide consent or express her wishes, the ombudsman should review the family member’s power of attorney document to verify the type of authority the family member has and at what point the powers go into effect. After determining that the family member is the legal decision maker for the resident, the ombudsman should handle the complaint about care and be guided by the family member.

## **VII. SUMMARY OF THE OMBUDSMAN ROLE WITH FAMILIES**

The role of the ombudsman when working with family members will vary depending on the resident’s capacity and the situation. Ombudsmen may serve as mediators, negotiators, educators, brokers, or consultants. When working with families, sometimes the most important role of the ombudsman is to provide them with support and information. Family members need someone outside of the long-term care facility who understands the regulations and knows about good care practices and how facilities operate. They need someone who can tell them that their concerns are valid and they are on the right track, or if not – to guide them. For families with a loved one in a long-term care facility, sometimes just knowing that they are not alone and that another person understands the difficulties they are facing can make all the difference.

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## **WORKING WITH FAMILIES:**

**TIPS FOR EFFECTIVE COMMUNICATION AND  
STRATEGIES FOR CHALLENGING SITUATIONS**

## **RESOURCES**



## RESOURCES

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## OVERVIEW OF KEY COMMUNICATION TECHNIQUES

Ombudsmen refine their communication skills during their initial certification training. Basic elements of communication contained in the National Long-Term Care Ombudsman Resource Center (NORC) Curriculum are highlighted below. While the curriculum primarily focuses on communication with residents, many of the same techniques apply or can be adapted to communication with family members.

In addition to the techniques presented in ombudsman training materials, there are other techniques described below. These techniques were selected due to their usefulness in problem-solving and conflict resolution.

### I Statements<sup>1</sup>

These are statements in which a person “owns” what she says and does not claim to be speaking for others. They are also a way for a person to express what she wants and needs without blaming another person or making her defensive.

The composition of I-statements can vary. One approach is to use I-statements that have the following components:

- **The action**  
In this part of the I-statement, you describe what is happening in an objective way because the other person may not interpret actions in the same way as you.
  - The word “when” can be very helpful.
  - Avoid the use of “you” because it makes people feel they are being accused.
  - Avoid emotive words that are tied to a person’s perception.  
For instance, when you say that someone “barged” into the room, the word “barged” carries a negative overtone and the other person may not perceive her entry into the room in that way. You could express this more neutrally by saying that the other person came into the room suddenly.
- **Your response**  
The purpose of this part of the I-statement is to convey your feelings because the other person may have no idea how you are feeling.
  - Can use “I feel” or I feel like.”
- **Your preferred outcome**

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<sup>1</sup> Conflict Resolution Network. *Conflict Resolution (CR) Trainers’ Manual: 12 Skills*. 2008.  
<http://www.crnha.org/pages.php?plD=77>

The last part of the I-statement is to define the outcome that you would like without specifying how it has to be done.

**Example:**

**Instead of saying:** “You’re making me so frustrated when you interrupt me,”

**Say:** “When I am not able to finish what I’m saying, I feel frustrated and what I’d like is to be able to communicate my complete thought.”

### Open-ended Questions

Asking questions allows a person to gain and clarify information and perceptions. A “closed” question is good for gathering very specific information when all you want is a yes or no. However, in problem-solving and conflict resolution asking open-ended questions helps you build understanding and show empathy. These types of questions also encourage people to talk and provide more information –which is always helpful in problem-solving.

Interrogatives that help in asking open-ended questions include:

- How
- Tell me
- What

It is helpful to avoid using “why” because using “why” can appear confrontational and make the respondent feel defensive.

**Example:**

**Instead of saying:** “Why wasn’t your work completed today?”

**Say:** “Help me understand the reasons your work did not get completed today.”

### Reflective Listening<sup>2</sup>

Reflective listening or responding is the process of restating in our own words the content and/or feeling of what someone has said. It does not mean that you agree with the speaker. By reflecting back to the speaker what you believe you understand, you validate and affirm that person by giving them the experience of being heard and acknowledged. You also provide an opportunity for the speaker to give you feedback about the accuracy of your perceptions, thereby increasing the effectiveness of your overall communication.<sup>3</sup> Reflective listening is one of the most important steps you can take in problem-solving and conflict resolution, because it indicates that you are truly listening and seeking to understand the other person.

#### **Types of reflective listening:**

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<sup>2</sup> Much of this section is adapted from Rod Windle and Suzanne Warren’s *Collaborative Problem Solving and Dispute Resolution in Special Education*. The National Center on Dispute Resolution in Special Education.

<http://www.directionservice.org/cadre/section4.cfm>

<sup>3</sup> Windle and Warren, *ibid*.

**Paraphrasing.** This is a concise statement of the content of the speaker's message. A paraphrase should be brief, succinct, and focus on the facts or ideas of the message rather than the feeling. The paraphrase should be in your own words instead of just repeating exactly what the speaker has said.

**Reflecting Feeling.** This approach involves identifying the feeling under the speaker's words and then reflecting the feeling back to the speaker in a way that conveys understanding.

**Summarizing.** In this type of reflective listening, you combine paraphrasing and reflecting feeling. You pull together the main ideas and feelings of the speaker to show understanding. This skill is used after a considerable amount of information sharing has gone on and shows that the listener grasps the total meaning of the message. It also helps the speaker gain an integrated picture of what he or she has been saying.<sup>4</sup>

**Example:**

**Situation:** In response to concerns you share about food service the administrator says the following:

"We've had a lot of trouble with our dietary department lately. We can't seem to keep our food services supervisor for more than a few weeks. You have to understand that we're doing the best we can."

To **paraphrase** what the administrator said, you could say:

"Your food services supervisors keep leaving and this is creating problems in the dietary department."

To **reflect feeling**, you could say:

"You're frustrated because the turnover in food services supervisors is affecting the functioning of the dietary department."

To **summarize**, you may say:

"You're frustrated because you're having problems in the dietary department due to the turnover of food services supervisors. You feel that your staff is doing everything they can in the circumstances and hope that I will be patient during this time."

**Power of "we"**

When you say "we" in your conversation, it creates a sense of team and partnership between you and a family member or between a family member and the facility administration and staff. This sends a

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<sup>4</sup> Windle and Warren, *ibid*.

message that it is all of you working together to make sure a resident gets good care – it's not you on one side and staff on the other. This can send an important message and can help break down walls.

**Example:**

**Instead of saying:** “What are you doing to address this issue?”

**Say:** “Can we talk about what we can do to address this issue?”

### **Additional Resources**

#### **The National Long-Term Care Ombudsman Center (NORC) Curriculum**

This curriculum is designed to help states improve their basic training for local long-term care ombudsmen (LTCO). The teaching methods are based on principles of adult learning and grounded in LTCO values such as being resident directed.

<http://www.ltombudsman.org/ombudsman-support/training#Curriculum>

*The curriculum includes the following modules:*

#### **The Aging Process**

Provides tips for communicating with individuals with various illnesses or limitations such as communicating with someone who has difficulty hearing.

<http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/The-Aging-Process.pdf>

#### **Residents' Rights**

Emphasizes talking with the resident, letting the resident guide the ombudsman instead of the ombudsman making decisions and telling the resident what the ombudsman will do for him/her (individual resident) and thinking about the setting for communication (for privacy).

<http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/Local-ResidentsRights-CurriculumResource.pdf>

#### **The Problem Solving Process: Investigation and Resolution (two modules)**

Covers listening, establishing the setting for communication (for interviews and for resolution meetings), choosing times for serious conversation, being respectful of other people's time constraints (speaking with staff), different types of questions and the purpose of each, communication tips for building trust, and the “Point, Evidence, Repeat Point” approach which teaches effective communication strategy for resolving problems.

**Investigation Module:** <http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/Local-Investigation-Curri-cResource-Material.pdf>

**Resolution Module:** <http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/Local-Resolution-Curriculum-Resource-Material.pdf>

#### **State Ombudsman Program Certification Manuals**

There are examples of state LTCOP training and certification manuals on the NORC website and the manuals often have chapters or sections devoted to effective communication.

<http://www.ltombudsman.org/ombudsman-support/training#Manuals>

*Working with Families:*

*Tips for Effective Communication and Strategies for Challenging Situations*





## Long-Term Care Ombudsman Program

### WHAT IS THE LONG-TERM CARE OMBUDSMAN PROGRAM?

Long-term care ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. They work to resolve problems of individual residents and to bring about changes at the local, state, and national levels to improve care. While many residents receive good care in long-term care facilities, others are neglected, and other unfortunate incidents of psychological, physical, and other kinds of abuse do occur. Thus, thousands of trained staff and volunteer ombudsmen regularly visit long-term care facilities, monitor conditions and care and provide a voice for those unable to speak for themselves.

The Swedish word “ombudsman” means “a public official appointed to investigate citizens’ complaints against local or national government agencies that may be infringing on the rights of individuals.” This concept has been applied in many U.S. settings to include complaints against non-governmental organizations and advocacy for individuals and groups of individuals, as with the Long-Term Care Ombudsman Program.

### HISTORY

Begun in 1972 as a demonstration program, today the Long-Term Care Ombudsman Program is established in all States under the Older Americans Act which is administered

by the Administration on Aging (AoA). Local ombudsmen work with and on behalf of residents in hundreds of communities throughout the country.

### RESULTS

In federal fiscal year 2011, over 12,000 volunteers, 9,065 of whom were certified to investigate complaints, and 1,186 staff served in Long-Term Care Ombudsman Programs in 576 localities nationwide. Ombudsmen investigated and worked to resolve 204,044 complaints made by 134,775 individuals. In addition, ombudsmen provided information on rights, care and related services 403,701 times.

### RESIDENTS’ RIGHTS

Ombudsmen help residents and their families and friends understand and exercise rights guaranteed by law, both at the Federal level and in many States. Residents have the right to:

- Be treated with respect and dignity
- Be free from chemical and physical restraints
- Manage their own finances
- Voice grievances without fear of retaliation
- Associate and communicate privately with any person of their choice

# FACTS

- Send and receive personal mail
- Have personal and medical records kept confidential
- Apply for State and Federal assistance without discrimination
- Be fully informed prior to admission of their rights, services available, and all charges
- Be given advance notice of transfer or discharge

## OMBUDSMAN RESPONSIBILITIES

Ombudsman responsibilities outlined in Title VII of the Older Americans Act include:

- Identify, investigate, and resolve complaints made by or on behalf of residents
- Provide information to residents about long-term care services
- Represent the interests of residents before governmental agencies
- Seek administrative, legal, and other remedies to protect residents
- Analyze, comment on, and recommend changes in laws and regulations pertaining to the health, safety, welfare, and rights of residents
- Educate and inform consumers and the general public regarding issues and concerns related to long-term care and facilitate public comment on laws, regulations, policies, and actions
- Promote the development of citizen organizations to participate in the program

- Provide technical support for the development of resident and family councils to protect the well-being and rights of residents
- Advocate for changes to improve residents' quality of life and care

## RESOURCES

The National Long-Term Care Ombudsman Resource Center supported with AoA funding and operated by the National Consumer Voice for Quality Long-Term Care, in conjunction with the National Association of States United for Aging and Disabilities, provides technical assistance and intensive training to assist ombudsmen in their demanding work.

To contact a long-term care ombudsman, visit the resource center's Web site at <http://www.ltombudsman.org>.

You can also call AoA's Eldercare Locator at 1-800-677-1116 (<http://www.eldercare.gov>) and ask for the local ombudsman program or the Area Agency on Aging nearest the nursing home or similar adult care facility where the resident lives. The area agency will either be the sponsor of the ombudsman program or know where the program is located.

The *Medicare Guide to Choosing a Nursing Home* booklet is available free from the Centers for Medicaid and Medicare Services (CMS). Call 1-800-Medicare (1-800-633-4227) and ask for publication #02174, or view it on the Web at: <http://www.medicare.gov/NHCompare>.

FOR MORE INFORMATION ABOUT AOA

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ADMINISTRATION ON AGING, WASHINGTON DC 20201

PHONE: 202.619.0724 | FAX: 202.357.3555 | EMAIL: [AOAINFO@AOA.GOV](mailto:AOAINFO@AOA.GOV) | WEB: [HTTP://WWW.AOA.GOV](http://WWW.AOA.GOV)  
FACEBOOK: [HTTP://WWW.FACEBOOK.COM/AOA.GOV](http://WWW.FACEBOOK.COM/AOA.GOV)





## FREQUENTLY ASKED QUESTIONS ABOUT THE LONG-TERM CARE OMBUDSMAN PROGRAM (LTCOP)

### What is the role of the ombudsman?

The primary responsibility of the LTCOP is to serve as the resident advocate. The role of the ombudsman is not to do the job of other agencies, but to get them to do their job in a way that works for residents.

Long-Term Care Ombudsmen...	
<b><u>Do not</u> conduct licensing and regulatory inspections or investigations</b>	<ul style="list-style-type: none"> <li>• LTCO are knowledgeable of federal and state regulations and will refer to the relevant regulations as they advocate for the highest quality of care and life of residents.</li> <li>• If necessary, with resident consent, LTCO will file a complaint with licensing and regulatory.</li> </ul>
<b><u>Are not</u> Adult Protective Services (APS) investigators</b>	<ul style="list-style-type: none"> <li>• LTCO provide information regarding preventing and reporting abuse, neglect and exploitation.</li> <li>• LTCOPs do not have the same standard of evidence requirement as APS. LTCOPs attempt to resolve complaints to the residents' satisfaction, not gather evidence to substantiate that abuse occurred.</li> <li>• The LTCOP investigation process regarding allegations of abuse varies by state. However, most LTCOPs refer complaints about abuse to the appropriate state agency.</li> <li>• If necessary, with resident consent, LTCO will file a complaint about alleged abuse or advise another individual to do so.</li> </ul>
<b><u>Do not</u> provide direct care for residents</b>	<ul style="list-style-type: none"> <li>• LTCO share information about quality care practices and ways to enhance the quality of life for residents.</li> <li>• LTCO are a resource for staff training and provide information for community resources.</li> </ul>
<b>In addition to working to resolve complaints on behalf of residents, ombudsmen:</b>	<ul style="list-style-type: none"> <li>• Educate consumers about residents' rights, good care practices, and other related topics.</li> <li>• Provide information to the public regarding long-term care facilities and services, residents' rights, and legislative and policy issues.</li> <li>• Educate providers about residents' rights, good care practices, preventing abuse and neglect and other issues regarding quality of life and quality of care.</li> <li>• Help develop and support resident and family councils by providing information and assistance in starting or strengthening a council.</li> <li>• Advocate for improvements in the long-term care system that will benefit residents of long-term care facilities.</li> </ul>

### **Who is the Long-Term Care Ombudsman's (LTCO) client?**

The resident is the ombudsman's client. The Older Americans Act (OAA), a federal law that gives ombudsmen their authority, requires ombudsmen to represent the interests of residents. LTCO support resident-centered care and residents guide all LTCO work. The OAA requires that LTCO have resident consent prior to investigating a complaint or referring a complaint to another agency. When someone other than the resident files a complaint, the ombudsman must determine, to the extent possible, what the resident wants.

### **After I bring a concern to the ombudsman, what will the ombudsman do next?**

After receiving the complaint, the ombudsman will visit the resident in order to understand the resident's capacity to make decisions. Many residents, even residents with dementia, are able to express their wishes. If the resident wants the ombudsman to act on the problem the ombudsman will investigate the complaint and continue to communicate with the resident throughout the investigation process.

### **What happens if a resident is not able to give direction to the ombudsman?**

If the resident cannot indicate to the ombudsman what he or she would like and is not able to provide consent, the ombudsman assumes the resident would want his or her health, safety and welfare protected. The ombudsman will then work with you as the complainant.\* However, if the complaint requires the ombudsman to review the resident's health or financial records and you do not have the legal authority to access those records, the ombudsman must request permission from the person who does have proper authority.

*\* If the complainant is not the legal representative for the resident, the ombudsman would speak with the resident's legal representative before proceeding with the complaint.*

### **What are some reasons why the ombudsman may not be able to act on my concern?**

As noted above, one of the reasons would be if the resident did not think there was a problem or did not want the ombudsman to do anything. Other reasons may include:

- The resident does not give the LTCO permission to move forward with the complaint and the complaint does not impact other residents.
- The complaint does not fall within the scope of the LTCOP (e.g. the complaint needs to be investigated by the state agency that regulates long-term care facilities).
- The resident moved out of the facility or passed away before the LTCOP received the complaint.

Although the resident may not provide consent to pursue a complaint there are other actions ombudsmen can take that will both honor her confidentiality and work to ensure that she is receiving quality care and is protected from harm. Such actions may include:

- During future visits the ombudsman asks the resident if she has changed her mind about pursuing the complaint
- If the ombudsman observes the problem themselves they can pursue the complaint as the complainant

### **What are my options if the resident does not feel there is a problem or does not want anything to be done?**

You could speak with the facility staff yourself or file a complaint with the state agency that regulates long-term care facilities. In some cases, if the ombudsman believes your complaint impacts other residents, he or she may pursue a broader investigation that would not reveal your loved one's identity.

**What does the LTCO investigation include?**

The investigation process depends on the nature of the problem. The LTCO may interview residents, families and staff, observe conditions and care, and review documents. The purpose of the investigation is to determine if there is information to support the complaint and to gather the information needed to try to resolve it to the residents' satisfaction.

**Will the ombudsman tell the facility staff that I've filed a complaint about my loved one's care?**

Not unless you give your permission. Under federal law, the ombudsman cannot disclose the identity of the person making the complaint unless that person consents. However, depending on the nature of the complaint, the ombudsman's investigation into the problem and efforts to resolve it may be limited if he or she can't reveal your identity. If that is the case, the ombudsman will do as much as possible without revealing your identity and then talk with you about where to go from that point.

**Will the ombudsman tell me what he or she finds after investigating my complaint?**

Yes, if you are the complainant and the resident allows the LTCO to share the results with you. The resident controls the information that is found during the investigation and this information will only be shared with the resident's consent.

**What can I do if I have concerns about how my local ombudsman has handled my complaint?**

Start by talking to your ombudsman and explaining your concerns. If you are still dissatisfied after that, speak with the ombudsman's supervisor. If the supervisor's response is unsatisfactory, contact the State Ombudsman. To find the name and contact information for the State Ombudsman visit [www.ltcombudsman.org](http://www.ltcombudsman.org) and click on "Locate an Ombudsman."

## RESIDENTS' RIGHTS: AN OVERVIEW

April 2011

**Residents' Rights** are guaranteed by the federal 1987 Nursing Home Reform Law. The law requires nursing homes to ***"promote and protect the rights of each resident"*** and places a strong emphasis on individual dignity and self-determination. Nursing homes must meet federal residents' rights requirements if they participate in Medicare or Medicaid. Some states have residents' rights in state law or regulation for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. A person living in a long-term care facility maintains the same rights as an individual in the larger community.

### Residents' Rights Guarantee Quality of Life

The 1987 Nursing Home Reform Law requires each nursing home to care for its residents in a manner that promotes and enhances the quality of life of each resident, ensuring ***dignity, choice, and self-determination***.

All nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." ***This means a resident should not decline in health or well-being as a result of the way a nursing facility provides care.***

The 1987 Nursing Home Reform Law protects the following rights of nursing home residents:

#### The Right to Be Fully Informed of

- Available services and the charges for each service
- Facility rules and regulations, including a written copy of resident rights
- Address and telephone number of the State Ombudsman and state survey agency
- State survey reports and the nursing home's plan of correction
- Advance plans of a change in rooms or roommates
- Assistance if a sensory impairment exists
- Residents have a right to receive information in a language they understand (*Spanish, Braille, etc.*)

#### Right to Complain

- Present grievances to staff or any other person, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- To complain to the ombudsman program
- To file a complaint with the state survey and

certification agency

#### Right to Participate in One's Own Care

- Receive adequate and appropriate care
- Be informed of all changes in medical condition
- Participate in their own assessment, care-planning, treatment, and discharge
- Refuse medication and treatment
- Refuse chemical and physical restraints
- Review one's medical record
- Be free from charge for services covered by Medicaid or Medicare

#### Right to Privacy and Confidentiality

- Private and unrestricted communication with any person of their choice
- During treatment and care of one's personal needs
- Regarding medical, personal, or financial affairs



## **Rights During Transfers and Discharges**

- Remain in the nursing facility unless a transfer or discharge:
  - (a) is necessary to meet the resident's welfare;
  - (b) is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
  - (c) is needed to protect the health and safety of other residents or staff;
  - (d) is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
- Receive thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care ombudsman
- Safe transfer or discharge through sufficient preparation by the nursing home

## **Right to Dignity, Respect, and Freedom**

- To be treated with consideration, respect, and dignity
- To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- To self-determination
- Security of possessions

## **Right to Visits**

- By a resident's personal physician and representatives from the state survey agency and ombudsman programs
- By relatives, friends, and others of the residents' choosing
- By organizations or individuals providing health, social, legal, or other services
- Residents have the right to refuse visitors

## **Right to Make Independent Choices**

- Make personal decisions, such as what to wear and how to spend free time
- Reasonable accommodation of one's needs and preferences
- Choose a physician
- Participate in community activities, both inside and outside the nursing home
- Organize and participate in a Resident Council
- Manage one's own financial affairs

### ***Advocates for Residents Rights***

Where do you go for help if you're concerned a facility is not guaranteeing the rights of residents? Contact your local or state long-term care ombudsman or, if one exists, your state's citizen advocacy group. The Long-Term Care Ombudsman Program is required by federal law to promote and protect the rights of residents in licensed long-term care facilities. The Consumer Voice can help you locate advocates and ombudsmen in your area. Visit our website: [www.theconsumervoice.org](http://www.theconsumervoice.org) to view a map listing ombudsmen and citizen advocacy groups nationwide.

More fact sheets and publications on how to get good care in nursing homes are available by calling the Consumer Voice at 202.332.2275 or visiting our website at [www.theconsumervoice.org](http://www.theconsumervoice.org)

**Nursing Homes: Getting Good Care There,**  
\$11.95

#### **Fact Sheets:**

*A Consumer Guide to Choosing a Nursing Home:*  
*Restraints*  
*Access and Visitation*  
*Involuntary Transfer and Discharge*

*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

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## FAMILY MEMBER RIGHTS AND DECISION MAKING<sup>5</sup>

### Family Member Rights

When residents are not able to exercise their own rights, family members who are guardians or legally considered to be the resident's representative can exercise the resident's rights. This applies to many, but not all, family members.

As relatives of a resident in a nursing facility, federal regulations provide family members with the rights and protections listed below.\* However, in instances where the family's wishes are contrary to the resident's wishes, and the resident has the legal capacity to make decisions, the facility must uphold the resident's decision.

- Unless the resident exercises her right to privacy and does not want to notify or include her family, as a family member, you have the right to:<sup>6</sup>
  - Participate in the development of the resident's care plan;
  - Be notified when there is -
    - an accident involving the resident
    - a significant change in the resident's condition
    - a need to alter treatment
    - a change in room or roommate
    - a change in residents' rights
- Before transfer or discharge, the facility must provide written notice of the proposed transfer or discharge to the resident and, if known, a family member or legal representative. Prior to transfer (due to hospitalization or therapeutic leave) the facility must provide written notice of the state and facility bed-hold policies to the resident and, if known, family member or legal representative.
- Residents may receive visitors at any time of day or night. Family members have the right to form family councils in which they come together to work for improvements in the quality of care and quality of life of their loved ones. They have the right to meet in the facility with the families of other residents in the facility.

*\*Unlike nursing homes, assisted living facilities (also known as board and care homes) do not have federal requirements; therefore, assisted living facilities regulations vary by state and the federal regulations mentioned in this section only apply to family members with relatives in a nursing home.*

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<sup>5</sup> Much of this material has been adapted from the book, **Nursing Home Care in Suburban Cook County: A Family Caregiver's Guide**. Developed by Robyn Grant for the Suburban Cook County Ombudsman Program in Illinois and shared with the National Long-Term Care Ombudsman Resource Center.

<sup>6</sup> State Operations Manual. Appendix PP- Guidance to Surveyors for Long-Term Care Facilities. Centers for Medicare & Medicaid Services (CMS). Interpretive Guidelines 483.20(k)(2) and 483.10(b)(11).



### Decision-making Authority

Residents often execute a health care and/or financial power of attorney (POA) document. The resident or “grantor” designates an “agent” or “attorney-in-fact” (often a family member) to act on their behalf. The “powers” granted by the “grantor” depend on the type of power of attorney document. For example, a durable power of attorney means that the document is still valid when the grantor lacks the capacity to make decisions. If a resident lacks decision-making capacity and does not have an advance directive, state law will determine who has decision-making authority.

A POA does not automatically give the agent the right to make decisions for the grantor. The type of decisions an agent can make for the grantor depends on the powers stated in the POA and the capacity of the grantor. For example, if the POA is limited to financial decisions, the agent does not have the authority to make health care decisions. The agent should have a copy of the POA document and a copy should be in the resident’s chart.

Even if a resident has dementia or a limited capacity to make decisions, there may be times when she is able to indicate her preference in a particular situation. At those times, regardless of an individual’s legal authority, it is important to honor her preference whenever possible. Additionally, if a resident lacks the ability to make decisions or has been adjudged incapacitated by a court of law, she still has the right to be informed and be consulted regarding her preferences.<sup>7</sup>

**Regardless of a POA document, family members should advocate to ensure their loved one’s voice is heard and her wishes and choices are respected.**

- Make sure she is not left out of a conversation. If this happens bring attention back to the resident by asking her a question pertaining to the conversation. Do so repeatedly if necessary. Serve as a model to others.
- Encourage your loved one to speak up about her needs and preferences. You can do this by saying, “What do you think, Mom?” or “What would you prefer?”
- If staff members or other individuals are making decisions for the resident, say, “Let’s find out what Mom thinks.”

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<sup>7</sup> State Operations Manual. Appendix PP- Guidance to Surveyors for Long-Term Care Facilities. Centers for Medicare & Medicaid Services (CMS). Interpretive Guidelines 483.10(d)(3)



## TEACHING SELF-ADVOCACY TO FAMILIES: TIPS FOR OMBUDSMEN

As a means of empowering family members, long-term care ombudsmen provide problem-solving skills so they can advocate on their own behalf and that of their loved one.

1. Explain that your role will be that of a “coach” to guide and help them try to resolve the problem on their own.
2. Go over the **Problem-Solving Process for Families** handout. Explain that this document provides a framework to help guide them when trying to resolve a problem. Review the problem-solving stages and steps with them.
3. Direct the family member’s attention to the **Problem-Solving Worksheet for Families** and explain that this worksheet is the problem-solving table provided in a format that allows space for notes and documentation. Share the Problem-Solving Worksheet-EXAMPLE document and remind them that they can refer to this document as an example of the problem-solving process in the future.
4. Using the **Problem-Solving Worksheet for Families**, guide families through Stage 1.

Tips for guiding family members through Stage 1:

- Ask families to describe their problem with as much detail as possible.
- Ask questions to draw out relevant information. If families have kept a journal, they can pull details from their notes.
  - Depending on the problem, families might not have enough facts. It may be appropriate to encourage them to do some more observation and information gathering; and to document what they see and what occurs before moving forward.
- Explain the importance of a written statement:
  - Ensures family members have facts and details that will assist in resolution
  - Focuses on facts, not opinion
  - Provides a written statement that supports their complaint and can be submitted to the state survey agency or other entity if necessary
  - Gives family members talking points based on fact, not emotion, for when they discuss the problem with nursing home administration and staff
- Share the **Documentation Tips for Family Members** resource.
- Encourage family members to prepare **a written statement of their own problem**.
- Offer to review their written statement and provide feedback regarding the statement’s objectivity.
- Inform family members that they do not need a law/regulation that relates to their concern; however, connecting a problem to the relevant laws or regulations can:
  - Strengthen their case that the issue needs to be resolved
  - Provide increased leverage
  - Help them respond when a facility staff member says, “the State won’t let us do that.”

*Working with Families:*

*Tips for Effective Communication and Strategies for Challenging Situations*

- Give them more confidence because a law/regulation supports their advocacy

**5. Guide families through Stage 2 of the problem-solving process.**

Tips for guiding family members through Stage 2:

- Discuss the need to honor their loved one's wishes about what she would like to have happen and come up with a goal that is acceptable to both the resident and them.
- Use your experience to give family members feedback regarding the goal (e.g. make sure the goal benefits the resident).
- Share the **Strategies for Addressing Concerns in Long-Term Care Facilities** handout and, if necessary, work with family members to generate possible approaches that would be appropriate given the nature of their problem and the steps they have already taken. Review the approaches they generated for their problem, identify the pros/cons for each approach and discuss which approach may be the most appropriate for their concern.

**6. Explain that their next step is to address their concern using the approach they've chosen. To help them prepare for taking action, you may consider the following:**

- Review the following handouts with the family member:
  - **Guidelines For Presenting The Problem**
  - **Coaching-based Communication**
  - **Recommendations for Meeting with Facility Administration and Staff**
- Discuss potential resistance they may encounter from facility administration and staff regarding their concern and how to respond.

**7. Encourage the family member to document what happens when they address their concern and to contact your office if they need additional assistance after trying to resolve their concern.**



## THE PROBLEM-SOLVING PROCESS FOR FAMILIES

### The Problem-Solving Process for Families

#### Stage I: Defining the Problem

<b>Step 1: Identify the problem</b>	What exactly is the problem? Describe the problem with as much specific detail as possible.
<b>Step 2: Identify supporting information.</b>	What information do I have about the problem? Information can come from observation, discussion with a loved one or staff, documents, etc.
<b>Step 3: Write a statement of the problem with supporting information.</b>	Use objective, factual language (See “ <a href="#">Documentation Tips for Family Members</a> ”) when writing your statement and include information/evidence that supports your statement.
<b>Step 4: (Optional) Identify if there are any laws or regulations that address the problem.</b>	While you should voice any concern that you believe is a problem, it can strengthen your case and increase your confidence if you know what (if any) regulations are applicable. You can look up state and federal nursing facility regulations at <a href="http://www.hpm.umn.edu/nhregsPlus/index.htm">http://www.hpm.umn.edu/nhregsPlus/index.htm</a> or you can consult your local ombudsman.

#### Stage II: Analysis and Planning

<b>Step 5: Determine your goal</b>	What does (or would) my loved one want to happen? What is an acceptable resolution? What outcome will benefit your family member? Make sure the goal is realistic and benefits your loved one. For example, instead of setting a goal to get the charge nurse fired, determine what needs to be addressed and resolved regarding the charge nurse’s impact on your family member’s care.
<b>Step 6: Assess what has already been done</b>	Think about the steps that you have already taken to resolve this problem. Whom did you talk to, when was the conversation, what did they say? What, if anything, happened after speaking with them?
<b>Step 7: Consider possible approaches</b>	Identify what action you could take to try to solve the problem at this point. Examples of approaches include: <ul style="list-style-type: none"> <li>• Find out if there is a designated person on staff to handle complaints and then speak with that person</li> <li>• Speak with the charge nurse</li> <li>• Speak with the Director of Nursing</li> <li>• Speak with the Administrator</li> <li>• Discuss the problem during a care plan conference</li> <li>• Take the problem to the family council</li> </ul>

<b>Step 8: Identify the pros and cons of each possible approach you came up with in Step 7.</b>	Think through the “upside” and “downside” of the approaches you identified.
<b>Step 9: Choose an approach</b>	After weighing the pros and cons, decide on the approach you think would be best given the situation and what you are comfortable doing.
<b>Step 10: Act!!</b>	Take the action you decided on in Step 9. Follow up any discussion you had with facility administration or staff by sending a note summarizing the discussion and including any specific steps the nursing home stated it would take.
<b>Step 11: Evaluate the outcome</b>	<p>What is the result of your action? Is the problem resolved? Partially resolved? Not resolved?</p> <p>If the problem is resolved, thank the facility administration and staff.</p> <p>If the problem is only partially resolved or not resolved at all:</p> <p>a) Repeat Steps 7-11  <i>Possible approaches at this point include:</i> <ul style="list-style-type: none"> <li>• Meeting with the administrator</li> <li>• Writing a letter to the administrator and copying (“cc”) the corporate office and the ombudsman</li> <li>• Writing to and/or meeting with a regional manager or someone from corporate office (for-profit facilities)</li> <li>• Writing to or meeting with the facility’s board of directors (non-profit facilities)</li> <li>• Taking the issue to the family council or forming a council if one does not exist</li> </ul> </p> <p>b) Identify where you could turn for assistance  <i>Examples include:</i> <ul style="list-style-type: none"> <li>• The ombudsman program (to find a local ombudsman and other state agencies visit <a href="http://www.ltombudsman.org">http://www.ltombudsman.org</a>)</li> <li>• The state survey agency to file a complaint (to find your state survey agency and other state agencies visit <a href="http://www.ltombudsman.org">http://www.ltombudsman.org</a>)</li> <li>• A citizen advocacy group (CAG) if one exists in your state. (To find information regarding CAGs and locate a CAG , visit the Consumer Voice CAG webpage: <a href="http://www.theconsumervoice.org/advocate/advocacy-group-center">http://www.theconsumervoice.org/advocate/advocacy-group-center</a>)</li> </ul> </p>



## PROBLEM-SOLVING WORKSHEET FOR FAMILIES

*Developed by Robyn Grant, MSW*

*For additional tips and assistance in completing this worksheet, review the Problem-Solving Process for Families chart.*

### Stage 1: Defining the problem

#### 1. Identify the problem.

What exactly is the problem?

#### 2. Identify supporting information.

What information do you have about the problem(e.g. when the problem occurs or has occurred, where in the facility, at what time, who is involved, etc.)? Information can come from observation, discussion with resident or staff, documents, etc.

#### 3. Written statement of the problem with supporting information.

Use the information from the above to prepare a written statement describing the problem. Use objective, factual language when writing the statement (See handout **Documentation Tips for Family Members**)

*Note: This written statement is important because it:*

- *gives you talking points that you can use with the facility*
- *ensures you have the facts and details that will help with resolution*
- *provides you with something you can submit if necessary*
- *focuses on objective facts*

#### 4. Identify any laws or regulations that address the problem.

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To find state and/or federal nursing home regulations or state assisted living regulations visit [http://www.hpm.umn.edu/nhregsplus/NHRegs\\_by\\_State/By%20State%20Main.html](http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html) OR consult your local ombudsman. NOTE: While you should voice any concern that you believe is a problem, it can strengthen your case and increase your confidence if you know what (if any) regulations are applicable.

## **Stage 2: Analysis and planning**

### **5. Determine the goal.**

What does (or would) your loved one want to happen? What outcome will benefit your family member? What is an acceptable resolution? Identify a goal that you and your loved one both support and that is realistic.

**6. Assess what has already been done.** Identify the steps have you've already taken to resolve this problem (e.g. when did you address this concern, who did you speak with and what did they say, did you submit your concerns in writing).

### **7. Consider possible approaches.**

What are the different approaches you could take to try to solve the problem at this point? A few examples of approaches include the following:

- Find out if there is a designated person on staff to handle complaints and speak with that person
- Speak with the charge nurse
- Speak with the Director of Nursing
- Speak with the Administrator
- Discuss the problem at a care plan conference
- Take the problem to the family council

### **8. What are the pros and cons of each approach identified in #7?**

### **9. Choose an approach.**

Given what you've already done, the pros and cons of the different approaches, and your strengths and weaknesses, what is the best approach to addressing this problem?

## **Stage 3: Action and Follow-Up**

### **10. Act!**

Describe the steps taken to act on the problem.

### **11. Evaluate the outcome.**

Is the problem resolved? Partially resolved? Not resolved?

If the problem is only partially resolved or not resolved at all, what else can you try?

- a) Repeat Steps 7-11, selecting a different approach from the list in #7.

AND/OR

- b) Identify where you could turn for assistance. Examples include:

- The long-term care ombudsman program. To find a local ombudsman and other state agencies visit <http://www.ltombudsman.org>.
- The state survey agency to file a complaint. To find your state survey agency and other state agencies visit <http://www.ltombudsman.org>.
- A citizen advocacy group if one exists in your state. (To find information regarding CAGs and locate a CAG, visit the Consumer Voice CAG webpage: <http://www.theconsumervoice.org/advocate/advocacy-group-center>)





## PROBLEM-SOLVING WORKSHEET- EXAMPLE

*Developed by Robyn Grant and used with permission from United Senior Action of Indiana*

*This is an example of the Problem-Solving Worksheet when used to work through the problem-solving process.*

### Stage 1: Defining the problem

#### 1. Identify the problem.

What exactly is the problem?

*My mother is a resident at Morning Glory Nursing Home. She needs assistance to the bathroom every two hours. For the last two months, I've found her wet when I visit on the weekends. Each time I find her wet, I've asked an aide to clean her up. On two occasions I've have spoken with the weekend nurse about the problem and she told me that it would be addressed. I continue to find my mother wet on the weekends.*

#### 2. Identify supporting information.

What information do you have about the problem (e.g. when the problem occurs or has occurred, where in the facility, at what time, who is involved, etc.)? Information can come from observation, discussion with a loved one or staff, documents, etc.

*I have information from my own personal observation. In my journal I recorded the dates and times and where I found my mother wet. I also wrote down whom I talked to, their positions, and what they said.*

#### 3. Written statement of problem with supporting information.

Use the information from the above to prepare a written statement describing the problem. Use objective, factual language when writing the statement (review the **Documentation Tips for Family Members** resource)

*Note: This written statement is important because it:*

- *gives you talking points that you can use with the facility*
- *ensures you have the facts and details that will help with resolution*
- *provides you with something you can submit if necessary*
- *focuses on objective facts*

*I have found my mother, Alice Thomas, in Room 102 on the Pavilion Unit, wet when I visited her on the weekends over the past two months. Below are the dates, times and locations in which I have found my mother wet and the name of the nursing assistant that I asked to clean her up:*

*Saturday, September 5, 2009, 2:00 pm - her room.*

*Nursing assistant: Jeanie Peters*

*Sunday, September 6, 2009, 11:30 am – dining room*

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*Nursing assistant: Sue Johnson*  
*Saturday, September 12, 2009, 10:00 am – her room*  
*Nursing assistant: Mary Roberts*  
*Sunday, September 13, 2009, 4:00 pm – her room*  
*Nursing assistant: Rachel Jackson*  
*Saturday, September 19, 2009, 1:30 pm –her room*  
*Nursing assistant: Nancy Smith*  
*Sunday September 20, 2009, 3:00 pm – her room*  
*Nursing assistant: Lori Horton*  
*Saturday, September 26, 2009, 11:00 am - lounge*  
*Nursing assistant: Caroline Phillips*  
*Sunday, September 27, 2009, 2:30 pm – her room*  
*Nursing assistant: Sara Spencer*  
*Saturday, October 3, 2009, 9:15 am – dining room*  
*Nursing assistant: Tom Albertson*  
*Sunday, October 4, 2009, 10:30 am – her room*  
*Nursing assistant: Joan Davids*  
*Saturday, October 10, 2009, 1:00 pm – dining room*  
*Nursing assistant: Judy Peters*  
*Sunday, October 11, 2009, 3:45 pm – her room*  
*Nursing assistant: Alan Miller*  
*Saturday October 17, 2009, 12:00 pm – dining room*  
*Nursing assistant: Emma Moore*  
*Sunday October 18, 2009, 2:30 pm - lounge*  
*Nursing assistant: Abby Taylor*  
*Saturday October 24, 2009, 7:00 pm – her room*  
*Nursing assistant: Rebecca Newport*  
*Sunday October 25, 2009, 10:00 am – her room*  
*Nursing assistant: Julie Harris*

*On September 19, I brought this problem to the attention of the week-end RN, Jody Keller. She assured me that it wouldn't happen again.*

*On October 3, I spoke with Jody Keller again about the same concern. She told me that the problem would be addressed.*

*Prepared by Barbara Thomas, daughter of Alice Thomas, 10/27/09*

#### **4. Identify any laws or regulations that address the problem.**

To find state and/or federal nursing home regulations and state assisted living regulations visit [http://www.hpm.umn.edu/nhregsplus/NHRegs\\_by\\_State/By%20State%20Main.html](http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html) OR consult your local ombudsman. NOTE: While you should voice any concern that you believe is a problem, it can strengthen your case and increase your confidence if you know what (if any) regulations are applicable.

*This example has been completed using federal nursing home regulations, but you may want to review your state's nursing home regulations that relate to your concern. Depending on the situation, you may not need to include state and federal regulations when discussing your concerns with the facility as using one or the other may be sufficient.*

Regulations related to the problem:

(This scenario assumes that Alice Thomas is wet is because she has not received the assistance she needs to get to the bathroom.)

*Regulation #1*

- *Federal regulation: The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.*

*Regulation #2*

- *Federal regulation: A resident has the right to --*
  - *Reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health or safety of the individual or other residents would be endangered.*

*Regulation #3*

- *Federal regulation: The facility must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care.*

*Regulation #4*

- *Federal regulation: A facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident's quality of life.*

*Regulation #5*

- *Federal regulation: Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.*

*Regulation #6*

- *Federal regulation: A resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that diminution was unavoidable. This includes the resident's ability to --*
  - *Bathe, dress, and groom;*
  - *Transfer and ambulate;*
  - *Toilet;*
  - *Eat; and*
  - *Use speech, language, or other functional communication systems.*

## **Stage 2: Analysis and planning**

### **5. Determine the goal.**

What does (or would) your loved one want to happen? What outcome will benefit your family member? What is an acceptable resolution? Identify a goal that you and your loved one both support and that is realistic.

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*Mom can't tell me what she wants, but she has always been very fastidious about her looks and personal hygiene. She would be mortified to be wet. I think we want the same goal – for her to be kept clean and dry.*

**6. Assess what has already been done.** Identify the steps have you've already taken to resolve this problem (e.g. when did you address this concern, who did you speak with and what did they say, did you submit your concerns in writing).

*I asked the aide on duty each time to clean mother up. I also spoke with the weekend nurse twice - September 19 and October 3. She said she would take care of the problem.*

**7. Consider possible approaches.**

What are the different approaches I could take to try to solve the problem at this point? A few examples of approaches include the following:

- Find out if there is a designated person on staff to handle complaints and speak with that person
- Speak with the charge nurse
- Speak with the Director of Nursing
- Speak with the Administrator
- Discuss the problem at a care plan conference
- Take the problem to the family council

*I could:*

- *Find out if there is a designated person on staff to handle complaints and speak with that person*
- *Speak with the weekend nurse again*
- *Speak with the Director of Nursing (DON)*

**8. What are the pros and cons of each approach identified in #7?**

*Speak with the facility's designated staff person: Pro: I would be using the facility's own procedure. Con: This might delay the resolution because my concern would have to be channeled first to the right department.*

*Speaking with the weekend nurse again: Pro: This would show that I am really trying to work with her. Con: I've done this twice already and nothing improved. Going back to her would just delay fixing the problem.*

*Speak with the DON: Pro: The DON is the next person in the nursing department chain of command. It is the DON's job to make sure residents are getting proper care. The DON has the authority to address this problem. Con: The DON is very busy and it could be hard to set a time to talk with her.*

**9. Choose an approach.**

Given what you've already done, the pros and cons of the different approaches, and your strengths and weaknesses, what is the best approach to addressing this problem?

*I will speak with the Director of Nursing – that seems like the fastest and most direct approach - and she has the power to do something about the situation.*

### **Stage 3: Action and Follow-Up**

#### **10. Act!**

Describe the steps taken to act on the problem.

*I met with the Director of Nursing on October 29, 2009 and presented my concern using my written statement. I gave her a copy of the statement. She said she would review with staff the importance of keeping residents clean and dry, specifically address the issue with the weekend staff on your mother's wing, and ask the weekend charge nurse to monitor the situation and report back to her.*

#### **11. Evaluate the outcome.**

Is the problem resolved? Partially resolved? Not resolved?

*The problem is not solved. My mother was wet on October 31, November 1, November 7 and November 8.*

If the problem is only partially resolved or not resolved at all, what else can you try?

- a) Repeat Steps 7-11, selecting a different approach from the list in #7.

AND/OR

- b) Identify where you could turn for assistance. Examples include:

- The long-term care ombudsman program. To find a local ombudsman and other state agencies visit <http://www.ltombudsman.org>.
- The state survey agency to file a complaint. To find your state survey agency and other state agencies visit <http://www.ltombudsman.org>.
- A citizen advocacy group if one exists in your state. (To find information regarding CAGs and locate a CAG , visit the Consumer Voice CAG webpage: <http://www.theconsumervoice.org/advocate/advocacy-group-center>)

*I could:*

- *Talk to the administrator*
- *Go to the family council*
- *Contact the ombudsman*



## DOCUMENTATION TIPS FOR FAMILY MEMBERS

- Record the events in chronological order by date and approximate time.
- Be as specific as possible.
  - For example, say, “My mother is not receiving adequate fluids during the day shift,” instead of saying, “The care is terrible.”
- Include “who, what, when and where” information. For example, identify which room in the facility, name and title of staff person, date and time of any incident(s).
- Keep to the facts. Avoid opinions and personal feelings. Don’t include why you think the problem is happening – this is your opinion.
- Use quotes when possible, especially to capture the speaker’s attitude, opinions or observations.
- Use objective language.

**Example:**      Describe rather than label behavior.

Say:                “The Administrator said he had no comment when I asked about the training and supervision that CNAs receive. After my next question about the complaint, the administrator said the meeting was over and escorted me to the door.”

Don’t say:        “The Administrator was rude and unresponsive to my questions.”

**Example:**      Describe observations rather than draw a conclusion.

Say:                “I saw coffee and juice stains on the floor in the activity room on the second floor. The floor felt sticky to the touch.”

Don’t say:        “The floor was dirty and obviously had not been cleaned since breakfast.”

**Example:**      Use measurable terms (e.g. can be seen, counted or measured) rather than words that may have different meanings to different people.

Say: “Hit, run, cried, slept, does not speak, calls out repeatedly, smiles.”

Don’t say: “Depressed, abused, confused, stubborn, disrespectful, filthy, clean, and friendly.



## STRATEGIES FOR ADDRESSING CONCERNS IN LONG-TERM CARE FACILITIES

### Approaches to Problem Solving

Listed below are some approaches that you can take to address concerns in long-term care facilities. If possible, it is always a good idea to try to resolve the problem by speaking with the facility administration and staff first. *The steps below do not have to be followed in this order.*

***Speak with your loved one first to make sure she wants action to be taken regarding your concerns. Respect her preferences and wishes.***

1. Discuss the problem with facility staff.
  - Speak with staff supervisors or department managers.
  - Request a special meeting with the administrator.
2. Raise your concerns during the next care plan conference or request a special care plan conference.
3. Use the facility's grievance procedure.
4. Go up the ladder. Everyone has a boss. In a for-profit corporation, that may be a regional manager. In a non-profit facility, the administrator usually reports to the board of directors.
5. Raise the concern during a family council meeting or with the president of the family council.

### Seek Assistance from an Entity Outside of the Facility

If using one or a combination of the approaches listed above does not resolve the problem, there are organizations, agencies and programs you can turn to for help outside the long-term care facility.

### Long-Term Care Ombudsman Program (LTCOP)

Long-term care ombudsmen serve as advocates for residents in long-term care facilities (e.g. nursing home and assisted living facilities/board and care homes). Some state LTCOPs advocate for consumers of home and community based services. Ombudsman services are free and confidential. Ombudsmen:

- Investigate complaints, concerns or problems voiced by residents or their legal representatives;
- Provide information about residents' rights and facility responsibilities; and
- Advocate for improvements in the long-term care system.

To locate an ombudsman visit the National Long-Term Care Ombudsman Resource Center (NORC) at the link below and click "Locate an Ombudsman."

<http://www.ltcombudsman.org>

### State Survey and Enforcement Agency

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The survey and enforcement agency (also known as licensure and certification) investigates complaints about care, treatment, rights, staffing, food and other conditions and services for which the provider is responsible. However, the agency only investigates problems that relate to the federal and/or state regulations governing the long-term care facility. In many states, the survey agency is primarily responsible for investigating reports of abuse, neglect, or exploitation in long-term care facilities.

You can address your concern by:

- Speaking with the agency surveyors (inspectors) when they are inspecting the facility. You will know they are in the building because signs will be posted. You can ask to speak to the surveyors in private and share your concerns.
- Filing a complaint with the agency. Include detailed information in your complaint. Follow the guidelines in the **Documentation Tips for Family Members** information sheet.

To find the contact information for your state survey and enforcement agency visit the NORC website, click “Locate an Ombudsman” and the state agency information will be listed on the same page as the state ombudsman information.

<http://www.ltombudsman.org>

### **Other Agencies**

A number of other agencies may also be involved in assuring quality long-term care.

### **Adult Protective Services (APS)**

Adult Protective Services investigators investigate reports of abuse, neglect or exploitation of endangered adults. However, in some states, APS does not conduct investigations in nursing homes.

To find the contact information for your state Adult Protective Services agency visit the NORC website, click “Locate an Ombudsman” and the state agency information will be listed on the same page as the state ombudsman information.

<http://www.ltombudsman.org>

### **Medicaid Fraud Control Unit**

The duties of this unit include investigation of abuse and neglect of residents of long-term care facilities and theft of residents’ personal funds.

To find the contact information for your state Medicaid Fraud Control Unit visit the NORC website, click “Locate an Ombudsman” and the state agency information will be listed on the same page as the state ombudsman information.

<http://www.ltombudsman.org>.

### **Law Enforcement Agencies**

Local law enforcement agencies are responsible for investigating crimes *wherever* they occur. Should you believe that your loved one has been the victim of a crime in a long-term care facility, contact a local law enforcement agency immediately.

### **Protection and Advocacy Services (also known as Disability Rights Networks)**

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This agency works to address concerns about care, treatment and rights of residents who are developmentally disabled and/or mentally ill.

To find the contact information for your state protection and advocacy services agency visit the NORC website, click “Locate an Ombudsman” and the state agency information will be listed on the same page as the state ombudsman information.

<http://www.ltcombudsman.org>

### **Licensing Boards**

There are a variety of boards that license health professionals such as nursing home administrators, doctors, and nurses. These boards also investigate complaints filed against these health care professionals.

To find the contact information for your state survey agency visit the NORC website, click “Locate an Ombudsman” and the state agency information will be listed on the same page as the state ombudsman information.

<http://www.ltcombudsman.org>



## **RECOMMENDATIONS FOR MEETING WITH FACILITY ADMINISTRATION AND STAFF**

### **Prior to the meeting**

- Gather all the information you need about the concern(s) you want to address (e.g. use the Problem-Solving Process Worksheet).
- Determine what you will and will not accept regarding your concerns.
- It is important to remain flexible and open about how the problem can be resolved, but you may want to think about possible solutions to the problem to propose during the meeting, if necessary.
- Consider barriers or resistance you may encounter and how to overcome it.

#### **For example:**

- If the Administrator says, “We don’t have the staff to do that,” you could say, “How can we approach this in a way to best utilize the staff you do have?”
- If the Administrator says, “We can’t provide one-on-one care,” you could say, “I certainly understand the enormous job you have. Can we talk about how to address the issue/concerns without providing one-on-one care?”
- If the Director of Nursing says, “It’s not that staff don’t check on your mother regularly – you must be coming in right after she has been checked and has wet herself again,” you could say, “I can see how that could be the case with some residents, but in my mother’s situation I have found her with a dried urine stain on her dress indicating that the urine had been there so long it dried.” Can we talk about how to ensure that my mother is kept dry?”
- Understand that you may have a strong emotional response when discussing concerns about your loved one’s care and be prepared to do what is necessary to control those emotions before saying or doing something that may damage your ability to communicate effectively and work with the staff. For example, read from written notes during the meeting, count to ten, take a few deep breaths or excuse yourself from the meeting for a moment.

### **During the meeting**

- Before discussing your concerns, thank everyone for their time.
- Work to build rapport. You could say, “I know that quality of care is important to you for each of the residents in your facility and that you would want to know if anything is affecting that care. That’s why I wanted to bring my concern to you.”
- Describe the problem factually, objectively and without blame.

- Consider using an “I statement,” such as “When I find my mother wet, I get distressed, and what I would like is for her to be clean and dry.”
- Consider using the “power of we.” For example, “Can we talk about what we can do to make that happen?”
- Reflect back, paraphrase and summarize to show that you are listening to the needs and concerns of the administration and staff. Reflective listening does not mean that you agree with what is being said, just that you have heard it.
- Establish time frames – what will be done and by when.
- Ask whom you should go to if something that was agreed to is not working well.
- Take notes.

#### **After the meeting**

- Include your notes in the form of a thank you letter, summarize what was agreed to, send the letter to the staff and keep a copy.

## GUIDELINES FOR PRESENTING THE PROBLEM

Adapted from The PHI Coaching Approach<sup>SM</sup> to Supervision,  
with permission of the Paraprofessional Healthcare Institute, 2013. ([www.PHInational.org](http://www.PHInational.org))



1. **Describe the behavior—don't pass judgment on it.** For instance, rather than saying, “no one seems to be able to take the time to help,” say, “The last two times I have visited I have found my mother’s call bell going off and her needing to go to the bathroom. Can you tell me what is going on for this to be happening?”
2. **Be specific rather than vague.** For instance, rather than saying, “It has been like this all week,” say, “The last two times I have visited.”
3. **Describe what you observed rather than what you assume to be the reason it happened.** Focus on what happened rather than *why you think* it happened. For instance, don’t assume understaffing. Offer an explanation only if you know for certain it is true.
4. **Focus on a behavior rather than the person.** For instance, rather than saying, “I am beginning to think no one really cares here,” say, “Normally when I visit my Mom after work she is very comfortable and her needs are met. The last two times I visited her I have found her with the call bell going off and needing to go to the bathroom.”
5. **Don't avoid presenting the problem.** Be sure to address the problem behavior or situation even if the immediate situation is resolved.

## THREE RULES FOR PRESENTING THE PROBLEM

1. Be clear and direct about what the problem is.
2. Use objective language free from blame or judgment.
3. Indicate belief in the person’s ability to resolve the problem.

# **PHI COACHING APPROACH<sup>SM</sup> TO COMMUNICATION**

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## **Create a Relationship with the Other Person**

- Identify any of your own personal emotional triggers or listening blocks; use a pull-back strategy that works for you
- Find a good time to raise the issue
  - *Private setting*
  - *Careful timing*
  - *Distractions minimized*
- Indicate interest and belief in the other person
  - *Keep an open mind about the person*
  - *Keep an interest in the person, in understanding his or her reality*
- Use an inviting and encouraging tone of voice

## **Present the Problem**

- Be clear and direct about what the problem is
- Limit the statement to a single problem (not a list)
- Use objective language free of blame or judgment
- Emphasize your wish to resolve the problem positively
- Indicate your belief in the person's abilities, including his or her ability to resolve problems
- Reinforce the positive by pointing out the person's specific accomplishments and successes

## **Listen for the Other Person's Perspective**

- Put aside your own agenda while listening
- Listen actively to understand the person's perspective
- Acknowledge the person's perspective
- Paraphrase and use open-ended clarifying questions

## **Resolve the Problem with the Other Person**

- Maintain a focus on issue-related behaviors
- Reach mutual agreement on the nature of the problem
- Develop strategies together to address the problem

## **Obtain Commitment to Action Steps**

- Make mutual commitments for specific, measurable action steps
- Follow through on commitments

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## RESOURCES FOR FAMILY MEMBERS

This list includes resources that ombudsmen can use to educate families about nursing facility requirements, assisted living, resident rights, family rights and decision-making, family councils and advocating for quality care.

### Advocating for Quality Care

#### **Consumer Voice Fact Sheets**

Free fact sheets addressing a variety of care issues in the following four categories: selecting a nursing home, getting quality care, residents' rights and family involvement (e.g. Family Involvement in Nursing Home Care, Assessment and Care Planning: The Key to Good Care, Basics of Individualized Care).

<http://www.theconsumervoice.org/familymember/factsheets>

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care and the chapter, "Problem Solving: Being Your Own Advocate" discusses specific tips for self-advocacy.

<http://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

**Consumer Guide - Restraints: The Exception, Not the Rule - A Guide for Residents, Their Families and Friends to Promote Good Care in Place of Restraints in California Nursing Homes.** Sarah Greene Burger. Produced by The National Consumer Voice for Quality Long-Term Care, supported by a grant from the California HealthCare Foundation, based in Oakland, California.

This guide introduces residents, their families and friends to care practices that preclude the use of physical restraints. Although written for California, the information and care practices apply to nursing home care everywhere.

**Available here:** <http://www.theconsumervoice.org/sites/default/files/family-member/NCCNHR-Consumer-Guide-COLOR-FINAL.pdf>

**To order the national guide:** <https://www.theconsumervoice.org/catalog/restraints-the-exception-not-the-rule>

**CA Voices for Quality (additional resources for quality care):**

<http://www.theconsumervoice.org/familymember/family-council-center/ca-voices>

**Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy.** Consumer Voice. 2011.

This guide is designed for the individual who is currently receiving or who may in the future receive long-term services and supports. The purpose is to inform consumers about options for long-term services and supports. Its goal is also to empower - through education - to effectively advocate on one's own behalf.

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

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**20 Common Nursing Home Problems—and How to Resolve Them.** Eric M. Carlson. National Senior Citizens Law Center. 2010.

This popular guide explains problems commonly faced by residents and families and gives a clear explanation of the relevant law. It provides instructions on how a resident, family member or advocate should proceed if there's a problem.

<http://www.nsclc.org/wp-content/uploads/2011/02/20-Common-Problems-Nov-2010-Final.pdf>

**A Baby Boomer's Guide to Nursing Home Care.** Eric M. Carlson, Katharine Bau Hsiao. National Senior Citizens Law Center. 2006.

This guidebook takes a “nuts and bolts” approach to explaining the laws that protect nursing home residents and providing practical advice on how residents and their families can obtain the best nursing home care possible. *Available on Amazon.com and by other retailers.*

### **Advancing Excellence in America's Nursing Homes**

Consumer fact sheets on the following topics are available: pressure ulcers, restraints, pain, advance care planning, consistent assignment, staff retention, resident/family satisfaction and staff satisfaction. In addition, the *Advancing Excellence Guide for Consumer Participation* provides Family/Friend Worksheets on pressure ulcers, physical restraints, pain, resident and family satisfaction, and consistent assignment that build on the consumer fact sheets. The worksheets are designed to help families share key information about a loved one with nursing home staff and engage in a dialogue about how that information can be applied to a loved one's care.

[http://www.nhqualitycampaign.org/star\\_index.aspx?controls=consumer](http://www.nhqualitycampaign.org/star_index.aspx?controls=consumer)

### **Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes.**

Alzheimer's Association. 2006.

These care recommendations define goals in six care areas and present strategies for achieving them.

[http://www.alz.org/national/documents/brochure\\_dcprphases1n2.pdf](http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf)

### **Hartford Institute for Geriatric Nursing**

This website serves as an online resource for geriatric nurses. It includes information on many care areas. While the website is designed for nurses, the information can be very helpful to families.

<http://consultgerirn.org/resources>

### **Quality Improvement Organizations (QIOs)**

This website provides quality improvement information including resources and interventions developed by CMS.

**CMS QIO webpage:** <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityImprovementOrgs/index.html?redirect=/qualityimprovementorgs>

**Quality Net webpage (consumers can find their state QIO in the QIO directory):**

<http://www.qualitynet.org/dcs/ContentServer?c=Page&pagename=QnetPublic%2FPage%2FQnetHomepage&cid=1120143435363>

### **Assisted Living and Board and Care**

Unlike nursing homes, assisted living facilities (also known as board and care homes) do not have federal requirements; therefore, assisted living facilities regulations vary by state. The resources below provide advocacy tips and information regarding assisted living.

### **National Consumer Voice for Quality Long-Term Care (Consumer Voice) - Assisted Living Information**

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<http://www.theconsumervoice.org/resident/assisted-living/quality-care>

**National Long-Term Care Ombudsman Resource Center (NORC) - Assisted Living Issue page**

<http://www.ltombudsman.org/issues/assisted-living>

**Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy.** Consumer Voice. 2011.

This guide is designed for the individual who is currently receiving or who may in the future receive long-term services and supports. The purpose is to inform consumers about options for long-term services and supports. Its goal is also to empower - through education - to effectively advocate on one's own behalf.

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Assisted Living Consumer Alliance**

<http://www.assistedlivingconsumers.org/>

**Assisted Living State Regulatory Review.** National Center for Assisted Living.

<http://www.ahcancal.org/ncal/resources/Pages/AssistedLivingRegulations.aspx>

**Assisted Living Regulations and Licensing.** Assisted Living Federation of America (ALFA).

[http://www.alfa.org/alfa/State\\_Regulations\\_and\\_Licensing\\_Informat.asp](http://www.alfa.org/alfa/State_Regulations_and_Licensing_Informat.asp)

**NH Regulations Plus.** University of Minnesota. State Regulations by State (including state assisted living regulations).

[http://www.hpm.umn.edu/nhregsplus/NHRegs\\_by\\_State/By%20State%20Main.html](http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html)

**Effective Communication and Problem Solving Skills**

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care by discussing scenarios, sharing tips and resources for self-advocacy (e.g. Chapter 7- Problem Solving: Being Your Own Advocate), providing information regarding assessments and care plans and suggestions about providing helpful information to facility staff (e.g. Appendix 4" "I Want to Tell You About My Mother...").

<https://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

**Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy.** Consumer Voice. 2011.

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<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Tips for Effective Family Communication with Long-Term Care Staff and Administration.** Robyn Grant.

This short PowerPoint with speaking notes covers some of the communication techniques (I-statements, reflective listening, etc.) that are particularly helpful for problem solving. Includes some practice exercises.

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<https://www.ltombudsman.org/sites/default/files/norc/communication-for-families.ppt>

**20 Common Nursing Home Problems—and How to Resolve Them.** Eric M. Carlson. National Senior Citizens Law Center. 2010.

This popular guide explains problems commonly faced by residents and families and gives a clear explanation of the relevant law. It provides instructions on how a resident, family member or advocate should proceed if there's a problem.

<http://www.nslc.org/wp-content/uploads/2011/02/20-Common-Problems-Nov-2010-Final.pdf>

**A Baby Boomer's Guide to Nursing Home Care.** Eric M. Carlson, Katharine Bau Hsiao. National Senior Citizens Law Center. 2006.

This guidebook takes a "nuts and bolts" approach to explaining the laws that protect nursing home residents and providing practical advice on how residents and their families can obtain the best nursing home care possible. *Available on Amazon.com and by other retailers.*

**Guidelines for Presenting the Problem and PHI Coaching Approach<sup>SM</sup> to Communication.** PHI. Adapted from the PHI Coaching Approach<sup>SM</sup> to Supervision, with permission of the PHI, 2013.

([www.PHInational.org](http://www.PHInational.org))

These handouts provide helpful suggestions that families can use when speaking with facility staff about a concern.

<https://www.ltombudsman.org/sites/default/files/norc/guidelines-for-presenting-the-problem.pdf>

### **Missouri Miscommunication Training**

Developed by the Missouri LTCOP for Regional Volunteer Ombudsmen.

This material which was developed for ombudsmen can be adapted for teaching families how to avoid miscommunication.

[http://www.ltombudsman.org/ombudsman-support/training#Training\\_Programs\\_and\\_In-services](http://www.ltombudsman.org/ombudsman-support/training#Training_Programs_and_In-services)  
(under "Communication")

### **Family Councils**

#### **National Consumer Voice for Quality Long-Term Care (Consumer Voice)**

A wide range of materials regarding family councils is available Family Council Center on the Consumer Voice website. The resources include family council tips, laws and regulations, fact sheets, DVDs, manuals developed by ombudsman programs and citizen advocacy groups around the country, and more. Families can also join a free listserv available just for family council members.

**Family Council Center:** <http://www.theconsumervoice.org/familymember/family-council-center>

**Family Member webpage:** <http://www.theconsumervoice.org/familymember>

**Family Council Brochure.** Consumer Voice. 2010.

This brochure addresses empowered, effective and independent family councils. The brochure includes information about what a family council is, rights and best practices, resources and grant opportunities, and examples of family council activities. <http://www.ltombudsman.org/sites/default/files/2010-Family-Council-Brochure%281%29.pdf>

**Supporting Family Council Development.** Consumer Voice.

This training provides tips and ideas for developing and supporting family councils and an overview of nursing home regulations regarding family councils.

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<http://www.ltombudsman.org/sites/default/files/norc/issues/RR09-Training-Supporting-Fam-Council-Dev.pdf>

**Long-Term Care Ombudsman Guide to Developing and Supporting Family Councils.** Robyn Grant.  
<http://www.ltombudsman.org/sites/default/files/norc/issues/Omb-and-Family-Councils-LAFMC.pdf>

### **Family rights, Role, and Decision-making**

**Family Rights and Decision-making.** Robyn Grant.

This handout lists the rights that a family member of a nursing home resident has under federal law, talks about decision-making and powers of attorney, and outlines ways that families can support and empower a loved one.

<https://www.ltombudsman.org/sites/default/files/norc/family-member-rights-and-decision-making.pdf>

### **Nursing Facility Requirements**

**Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 or simply OBRA '87 SUMMARY.** Hollis Turnham. The National Consumer Voice for Quality Long-Term Care (Consumer Voice) *formerly NCCNHR*.

This summary discusses what OBRA is, how it came about and describes the major residents' rights provisions that are part of the law.

<http://www.ltombudsman.org/NORC-Library#laws> (titled "Summary" under "Nursing Home Reform Law of 1987")

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care.

<http://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

**Residents' Rights: An Overview.** Consumer Voice. 2011.

This fact sheet provides a description of residents' rights under the federal Nursing Home Reform Law.

<http://www.theconsumervoice.org/sites/default/files/resident/nursing-home/resident-rights-an-overview.pdf>

**Involuntary Transfer and Discharge.** Consumer Voice. 2007. National Consumer Voice for Quality Long-Term Care (Consumer Voice).

This fact sheet describes the federal protections that residents have in involuntary transfer/discharge situations.

[http://www.theconsumervoice.org/sites/default/files/advocate/advocacy-groups/involuntary transfer and discharge -7-08 update.pdf](http://www.theconsumervoice.org/sites/default/files/advocate/advocacy-groups/involuntary%20transfer%20and%20discharge%20-7-08%20update.pdf)

**Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy.** Consumer Voice. 2011.

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and supports. Its goal is also to empower - through education - to effectively advocate on one's own behalf.

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Nursing Homes Regulations Plus.** University of Minnesota.

Families can learn about federal nursing home regulations and their own state nursing home regulations on this website, which can be searched by topic.

<http://www.hpm.umn.edu/nhregsplus/>

**Federal Interpretive Guidelines.** Centers for Medicare & Medicaid Services.

The guidelines can educate families about what the nursing home should be doing and help identify questions to ask regarding nursing home life and care.

[http://www.cms.hhs.gov/manuals/Downloads/som107ap\\_pp\\_guidelines\\_ltcf.pdf](http://www.cms.hhs.gov/manuals/Downloads/som107ap_pp_guidelines_ltcf.pdf)

**20 Common Nursing Home Problems—and How to Resolve Them.** Eric M. Carlson. National Senior Citizens Law Center. 2010.

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