The National Long-Term Care Ombudsman Resource Center

WORKING WITH FAMILIES:

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TIPS FOR EFFECTIVE COMMUNICATION AND STRATEGIES FOR CHALLENGING SITUATIONS

ROBYN GRANT, MSW AMITY OVERALL-LAIB, MA

NATIONAL LONG-TERM CARE OMBUDSMAN CENTER

NATIONAL CONSUMER VOICE FOR QUALITY LONG-TERM CARE 1001 CONNECTICUT AVE, NW, SUITE 425 WASHINGTON, DC 20036 PHONE: 202-332-2275 EMAIL: <u>ombudcenter@theconsumervoice.org</u> www.ltcombudsman.org

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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 <u>for</u> residents and working <u>with</u> 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 <u>from</u> family members, one ombudsman noted that learning <u>about</u> 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 <u>residents'</u> interests, ombudsmen can use the following points to help explain why it is important that residents have confidentiality and that ombudsmen honor their wishes.¹

- 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.

¹ 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.²

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.

² 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 selfadvocacy 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 <u>them</u>. 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.³

³ 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 selfadvocacy, 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...."⁴ 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.⁵ The table below outlines a problem-solving process for families.

⁴ Residents' Rights, p. 6. Curriculum Resource Material for Local Long-Term Care Ombudsmen. Sara Hunt. National Long-Term Care Ombudsman Resource Center.

⁵ 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			
Step 1: Identify the problem	What exactly is the problem? Describe the problem with as much specific detail as possible.		
Step 2: Identify supporting information.	What information do you have about the problem? Information can come from observation, discussion with a loved one or staff, documents, etc.		
Step 3: Write a statement of the problem with supporting information.	Use objective, factual language (See the Documentation Tips for Family Members resource in the appendices) when writing your statement and include information/evidence that supports your statement.		
Step 4: (Optional) Identify if there are any laws or regulations that address the problem.	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 http://www.hpm.umn.edu/nhregsplus/NHRegs by State/By%20State%20Main.html.		
Stage II: Analysis and Planning			
Step 5: Determine your goal	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.		
Step 6: Assess what has already been done	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?		
Step 7: Consider possible approaches	 Examples of approaches include: Find out if there is a designated person on staff to handle complaints and then speak with that person Speak with the charge nurse Speak with the Director of Nursing Speak with the Administrator Discuss the problem during a care plan conference Take the problem to the family council 		
Step 8: Identify the pros and cons of each possible approach you came up with in Step 7.			
Step 9: Choose an	After weighing the pros and cons, decide on the approach you think would be best		

approach	given the situation and what you are comfortable doing.	
Step 10: Act!!	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.	
Step 11: Evaluate the outcome	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.	
	 If the problem is only partially resolved or not resolved at all: a) Repeat Steps 7-11 Possible approaches at this point include: Meeting with the administrator Writing a letter to the administrator and copying ("cc") the corporate office and the ombudsman Writing to and/or meeting with a regional manager or someone from corporate office (for-profit facilities) Writing to or meeting with the facility's board of directors (non-profit facilities) Taking the issue to the family council or forming a council if one does not exist 	
	 b) Identify where you could turn for assistance <i>Examples include:</i> The ombudsman program (to find a local ombudsman and other state agencies visit <u>http://www.ltcombudsman.org</u>) The state survey agency to file a complaint (to find your state survey agency and other state agencies visit <u>http://www.ltcombudsman.org</u>) 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: <u>http://www.theconsumervoice.org/advocate/advocacy-group-center</u>) 	

Ombudsmen can consult the **Teaching Self-Advocacy to Families: Tips for Ombudsmen** guide for stepby-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):

- <u>The Problem-Solving Process for Families:</u> 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.
- <u>Strategies for Addressing Concerns in Long-Term Care Facilities:</u> This handout is a concise outline of steps that family members can take to resolve a problem.
- **<u>Recommendations for Meeting with Facility Administration and Staff</u>: 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;
 - \circ if they need assistance in applying the problem-solving process to their concern; or
 - \circ $\;$ 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 comprising 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.⁶
- 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.

⁶ 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.⁷
- 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:

⁷ Ibid, p. 7

 Acknowledge what family members say they have experienced in the past and help to reestablish 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.⁸ 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.

⁸ "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; and 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; and ii) Acknowledges having been abused 	 i) Determine: Whether other residents have experienced similar circumstances; and Whether any other resident wishes the LTCO to take any action on his or her behalf; and 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; and ii) Visit the resident and follow complaint investigation steps
 i) Does not make the complaint; and ii) The LTCO personally witnesses abuse of a resident Requests the LTCO to not make a report of abuse personally witnessed by the LTCO 	 i) Report the alleged abuse witnessed by the LTCO to the appropriate agency; ii) File an ombudsman-generated complaint i) Determine: Whether other residents have experienced similar circumstances; and Whether any other resident wishes the LTCO to take any action on his or her behalf; and 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

Frequently, facilities call the ombudsman in cases of alleged <u>exploitation/abuse</u> 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 <u>http://www.ltcombudsman.org/sites/default/files/ombudsmen-support/training/2009-Actions-Ombudsmen-Can-Take-to-Prevent-Discharge.pdf</u> and additional resources regarding responding to elder abuse (including financial exploitation) <u>http://www.ltcombudsman.org/issues/elder-abuse-elder-justice</u> (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 heath 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 <u>would have been</u> 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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