

# “Difficult” is Not a Diagnosis

## What to Do When Your Loved One is Being Pushed to Take Antipsychotic Drugs

### ADVOCATE FACT SHEET

My mother recently moved into her nursing home. She has severe dementia, and I am her legal representative. Staff describe her as “difficult” because she hit a staff member and disturbs other residents. They are suggesting a new medication to control her outbursts. The staff have hinted if I say no, my mother will have to leave the nursing home.

### *In a nutshell*

“Difficult” is not a diagnosis and it is inappropriate to label any resident this way. Actions and behaviors are a form of communication by which residents are expressing an unmet need. There are a great deal of reasons that may explain your mother’s actions, and you do not have to agree to any treatment or medication you are uncomfortable with. There are steps the nursing home should take to assess and try to address what might be causing your mother’s behavior or distress before resorting to medication, such as an antipsychotic drug, for which she may not have a clinical diagnosis. The nursing home cannot discharge your mother without any notice. There is a process. Your mother has rights.

**Residents in your mother’s situation may not be able to express themselves using words. Instead, they express themselves through actions. Sometimes these actions are conveying “distress.” The response should be to identify the source of the distress and address it – not mask the symptoms with medications.**

*Anger, agitation, screaming, swearing, spitting, hitting, wandering, pacing, disrobing, crying, repetitive actions, unwanted sexual behavior*

### *What are her rights?*

Every person living in a nursing home has a right to quality, individualized care that meets their needs. The nursing home must provide care and services to help your mother “attain or maintain” her highest level of well-being – physically, mentally, and emotionally. This means the nursing home needs to work with your mother to determine how she can live her best life while in her facility.

You can ask the facility what’s changed that may have triggered the distress. Ask them to identify what the underlying cause might be. Could there be a medical reason? Is she in pain? Is your mother getting enough sleep? Was there an environmental change – is it too hot or cold? Is there a new roommate? Have there been changes to her routine? Has there been a change in medication? Figuring out the cause of the distress or need is necessary for finding an appropriate solution. A new assessment may be necessary.

Nursing homes must assess each resident and create a plan of care that spells out what care and services the person will receive to meet their needs, preferences, and goals. Care plans need to be re-evaluated every three months, or when there is a change in condition, to determine if something should be added or deleted from the plan. If your mother shows distress, or the facility suggests a new medication to control your mother’s behavior, request a care planning conference.

For more information about resident rights view the fact sheet [Nursing Home Residents’ Rights](#).

## What is a care planning conference?

A care planning conference is a meeting with staff from different departments where residents and their families talk about their needs and their life in the facility. All staff working with the resident should be involved in the conference. Medical and non-medical issues are addressed. By knowing the person's history, likes, dislikes, triggers, and comforts, staff can better meet their needs. Residents and their families can bring up problems, ask questions, and give the staff information. Talk about meals and activities that your mother likes and doesn't like, her schedule, her communication and physical abilities, and more. It's a place to raise concerns and develop solutions for things that are not working. The staff must talk to you about treatment decisions, like medications, and they can only do what you agree to.

## What should my role be during the care planning conference?

Make sure your mother's needs, preferences, and history are considered. Involve your mother, as much as possible, in the meeting. Find out what attempts have been made to resolve the problem. Gather more information by asking questions – such as, what was happening right before your mother reacted to the staff member, or about your mother's condition. Asking who, what, why, when, and where questions will help get to the root of your mother's distress. Below are some items the nursing home might mention in a care planning meeting and examples of some possible underlying causes:

What the nursing home observes	What might be happening	Find the reason for her actions, such as:
<b>Your mother is "hitting" a staff member</b>	She may be startled or afraid and feel the need to defend herself.	A staff member comes into your mother's room early in the morning while she's still asleep, pulls the blanket off of her, and begins pulling her clothes off to clean her up and get dressed for the day.  Your mother is startled and may push or hit them away in, from her perspective, self-defense.
<b>Your mother is crying out and disturbing other residents at night.</b>	She may be in pain or afraid.	Your mother is crying at night because she is in pain and is unable to ask for pain medicine or gets cold easily and needs another blanket but doesn't know how to ask for one.
<b>Your mother is unsettling residents, getting too close to them, and touching them.</b>	She may be confused, worried, seeking comfort.	Your mother may be looking for her family. She doesn't understand where you are and touches another resident thinking it may be you. She may be comforted by hearing your voice or being given something to hold and hug.

Determining the root cause of the actions or behaviors can help avoid confrontations in the future. If patterns or triggers for the actions are identified, a plan can be developed to address the need being expressed by your mother. Point out the need for a consistent routine and emphasize that she needs to be receiving person-centered care.

Your mother's behavior may indicate there is something wrong, or she needs attention. There are also ways that the staff could respond that would make your mother more comfortable. Below are a few examples of good care practices that staff should be engaging in.

## Good Care Practices

Good Care Practice	Staff should...
<b>Daily Care Adjustments</b>	<ul style="list-style-type: none"><li>• Describe what they are doing.</li><li>• Give simple instructions that they repeat frequently.</li><li>• Ensure they don't rush the resident.</li><li>• Treat the resident gently.</li><li>• Don't force activities that upset the resident.</li><li>• Stop the activity if the resident is upset.</li><li>• Give the resident space if they are upset.</li></ul>
<b>Distraction</b>	<ul style="list-style-type: none"><li>• Engage the resident in something they enjoy.</li><li>• Ask for help with certain tasks.</li><li>• Offer a snack.</li><li>• Invite the resident to walk with them.</li></ul>
<b>Environment Adjustment</b>	<p>Consider what within the resident's personal environment might be bothering them and ask questions:</p> <ul style="list-style-type: none"><li>• Is the lighting too much or too little?</li><li>• Is the room too hot or too cold?</li><li>• Is there too much noise or if the room is too quiet, would they like the radio or television turned on?</li><li>• Are they tired, or would they like to rest?</li></ul>
<b>Purposeful Activities</b>	<ul style="list-style-type: none"><li>• If a resident used to paint and can't hold a brush – offer to help them paint with sponges or give them clay.</li><li>• If a resident used to cook – have them help with easy tasks like stirring batter.</li><li>• If a resident enjoys caring for children – offer them a baby doll.</li></ul>

Request that staff try different ways of providing care or approaching your mother to see how she responds. You might even suggest a trial period to see how these approaches work. Set up time frames for using different interventions and set a plan for evaluating whether they are working. Facilities should be willing to try different interventions and try them more than once before resorting to medications. If use of an antipsychotic or psychotropic drug is proposed, ask what they expect this medication to do? Insist that non-pharmacological treatments be implemented. Be persistent. Remember, you don't have to agree to treatment you're uncomfortable with.

After the meeting, always ask for a copy of the care plan.

## ***What if we refuse the medication and the nursing home says my mother must leave?***

Under federal law, a nursing home cannot **transfer or discharge** a resident without a permissible reason. Reasons include that the facility cannot meet her needs, she no longer needs nursing home level of care, she is endangering the health or safety of others, she has not paid her nursing home bill, or the nursing home is closing. Often, in situations like these, the nursing home may argue that because your mother is “difficult,” they cannot provide adequate care, or they may say that her behavior is endangering other residents. These reasons can make families feel afraid or threatened, but remember, both reasons can often be addressed by understanding the reason or cause for the behavior. Remember, refusal of treatment alone, is not grounds for discharge.

If the facility attempts to transfer or discharge your mother for the reasons listed above, staff must document what specific need cannot be met, how the nursing home tried to meet that need, and the services in the new facility that can meet her needs. Additionally, they must provide written notice at least 30 days in advance except under certain very limited circumstances. You have the right to appeal the proposed discharge. You can contact your **Long-Term Care Ombudsman** (LTCO) to help you advocate. It is important to contact the LTCO as soon as possible after receiving the discharge notice. You can find an Ombudsman program in your area on our **website**.

## ***Isn't it easier to just agree to the new medication?***

No one should be given medication in place of good care or for the staff's convenience. In fact, when antipsychotic drugs are given to older adults with dementia, they can be unsafe. They often come with a black box warning, the most serious warning required from the US Food and Drug Administration, about their dangerous, life-threatening risks. Further, these drugs only mask the problem, they don't resolve the issue that is causing the distress.

Your mother deserves to have the staff work with you and her to find the underlying problem that's distressing her. When the problem has been identified, the staff can work to eliminate or alleviate it. See the list above of samples of good care practices. Examples of non-pharmacological treatments might be listening to music she likes, taking her for a walk, looking at a magazine or photo album, etc. Consider how staff are interacting with your mother. How are they approaching her and working with her? Are they surprising her? Do they give her time to orient herself to the situation? Do they take the time to explain what's happening to her? Are they gentle with her? All of this will make a difference in how your mother responds to her interactions with them. Working with and getting to know her caregivers may also help.

Once your mother feels secure and her needs are being met, the distress may go away.



## Are there other places to turn for help?

When a nursing home tells you that your family member is “difficult” or that she’s disturbing other residents, it may feel like your mother has done something wrong. She has not. It’s inappropriate for the facility to label a resident as “difficult.” It’s their job to evaluate and address her needs. You may feel like you’re all alone, but there are resources and supports that can help. You can talk directly with the nurse in charge or the director of nursing. You can speak with your mother’s personal doctor and the facility medical director. Beyond care planning and working with the facility, you have options.

### Family Councils

Determine if your nursing home has a **family council**. A family council is a group of family members and sometimes friends of residents who come together to share experiences, advocate, and communicate their concerns to their facility. Family councils can be an effective way to work for change and improvements in your facility. If no family council exists, you can join with other family members to start one.

### Long-Term Care Ombudsman Program

Reach out to your Long-Term Care Ombudsman program for help. Long-Term Care Ombudsmen are advocates who can work with you to advocate for your mother. They help resolve complaints and are good sources of information. You can find an Ombudsman program in your area on our [website](#).

### State Survey Agency

The State Survey Agency is responsible for overseeing nursing homes to ensure they are in compliance with state and federal standards. Residents and families have the right to complain and file a complaint with their state survey and certification agency when the resident’s rights are not being met. You can find their information here on our [website](#).

### More Resources

[My Personal Directions Worksheet](#)

[Resident Rights](#)

[The Misuse of Antipsychotics Among Nursing Home Residents](#)

[Know Your Drugs and Your Rights](#)

[Get the Facts about Antipsychotic Drugs and Dementia Care](#)

[Transfer/Discharge](#)

View the resources linked in this document by visiting:  
[theconsumervoiceworkshop.org/stop-chemical-restraints/resources](https://theconsumervoiceworkshop.org/stop-chemical-restraints/resources)

