

# Advocacy in Long-Term Care: Addressing Concerns About Retaliation



*Mrs. J yelled out and tried to push away the aide who was brushing her hair. The aide yelled at Mrs. J while hitting her on the arm with the brush and roughly pulling her hair.*

*Mr. P and his family noticed a decline in Mr. P's care, and they raised their concerns to the charge nurse. In the days after making the complaint, Mr. P noticed that his meals started coming later and later. He also noticed on several occasions, that while his call light was on aides walked by his room without stopping. When he asked to attend his weekly bingo game, Mr. P was told there was no one available to take him to play, but he noticed other residents on his floor attending activities as usual.*

*Mrs. S was told she had to go to bed early. When she protested, her aide threatened if she did not go now no one would help her if she rang her call bell or needed assistance later in the night.*

## How would you feel if this happened to you?

Retaliation, and the fear of retaliation, can prevent residents and family members from raising their concerns about care and safety. It also has a chilling effect on the reporting of abuse or neglect in long-term care facilities, leaving many living in fear and without relief from harm.

## Retaliation Can Take Different Forms

Examples include:

- **PSYCHOLOGICAL ABUSE** – A facility threatening or attempting to discharge a resident because they, or their family member, filed a complaint; or a staff member yelling or cursing at a resident after they were reported to the charge nurse for failing to provide care.
- **NEGLECT** – A staff person ignoring a resident or intentionally failing to provide care or assistance. Neglect can include unanswered call bells, late meals, ignoring resident requests, and intentionally not providing medication or assistance.
- **PHYSICAL ABUSE** – A staff member hitting, pinching, or being rough with a resident who does not follow directions or complains about something the staff member is doing.

Regardless of the form, retaliation by staff is abuse whether or not harm was intended.

## Is it Retaliation?

Retaliation can range from very subtle to obvious actions and it may be difficult to determine whether staff are retaliating or if a resident's needs are not being met for another reason, such as understaffing. How can you tell the difference?

Pay attention to changes in how a resident is treated, especially if the resident, or their family, has voiced concerns about care. Consider:

- Was there a change in the staff's treatment or response to the resident?
- Is the resident being singled out in some way?
- Are other residents' needs being met faster?
- Are staffing levels the same in the facility but suddenly the resident is being treated differently or receiving less care?
- Is the resident suddenly waiting a longer time for meals, forgotten when activities occur, or repeatedly the last one to receive services?

Retaliation is never acceptable, it is a violation of the residents' rights. There are action steps to take and ways to counter retaliation when it does occur. If the fear of retaliation silences a resident, or their family members, when there are problems in a facility this means those problems are likely to continue.

**“Retaliation is a very real thing, especially if you’re trying to advocate for others. Not receiving vital medications or food, or even having the facility cancel your appointments are just some of the ways a resident can be retaliated against.”**

*– Ebony, nursing home resident, Illinois*



## Know Your Rights

The right to a dignified existence, self-determination.

The right to exercise rights without interference, coercion, discrimination, or reprisal.

The right to be supported by the facility in the exercise of his or her rights.

The right to participate in the development and implementation of their plan of care.

The right to be treated with respect and dignity.

The right to form and participate in a resident or family council.

The right to voice grievances without discrimination or reprisal and without fear of discrimination or reprisal.

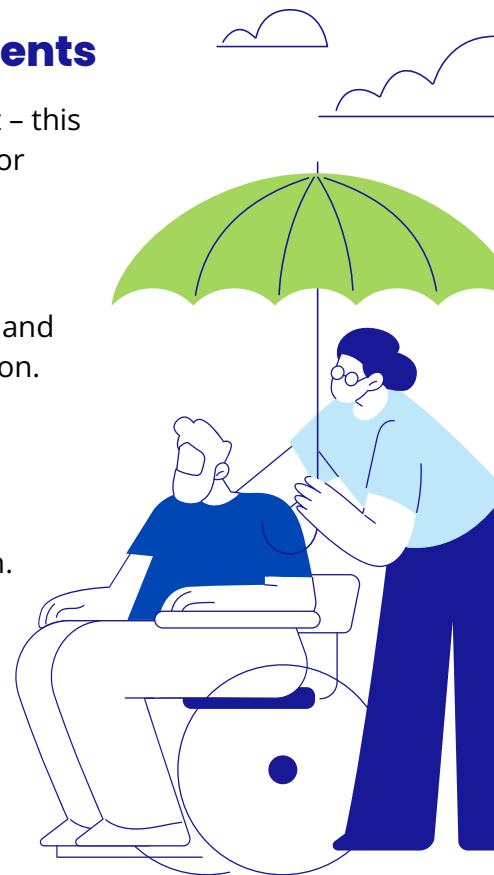
A facility must not prohibit or in any way discourage a resident from communicating with surveyors, long-term care ombudsman representatives, and protection and advocacy system representatives.

## Facilities Have a Responsibility to Protect Residents

The facility has a responsibility to protect residents from abuse and neglect – this includes protecting residents from retaliation. The facility, not the resident or family member, has the responsibility to stop retaliation from occurring.

To help prevent retaliation, facilities should:

- Adopt zero tolerance for retaliation. Communicate to residents, families, and staff that any suspected retaliation will be addressed by the administration.
- Invest in building positive relationships and open communication with residents, families, and staff. Support resident and family councils and engage in community building activities.
- Implement policies and procedures to prevent and respond to retaliation.
- Train staff about retaliation and the fear of retaliation so they know:
  - It may happen
  - It is always unacceptable
  - How to identify it
  - It must be reported
  - How and where to report it when they suspect that it is occurring
- Educate residents and families about Resident Rights, including their right to file grievances and complaints, and the process for doing so.
- Inform residents, families, and staff of resources about retaliation and the fear of retaliation. Ensure education on this topic continues beyond admission or initial hiring.



Recognize that residents and family members will have different levels of comfort in raising concerns or filing grievances. Their backgrounds, including factors such as race, religion, gender identity, physical and cognitive disabilities, socioeconomic status, and previous experiences, such as trauma, will influence how they react to different situations. Thus, the facility must ensure that all residents feel supported in speaking up.

## Overcoming the Fear of Retaliation and Getting Help

Retaliation should never happen. However, because fear of retaliation may prevent residents from speaking up, it is important to find ways for residents to feel comfortable and empowered to advocate within their facility. These can include:

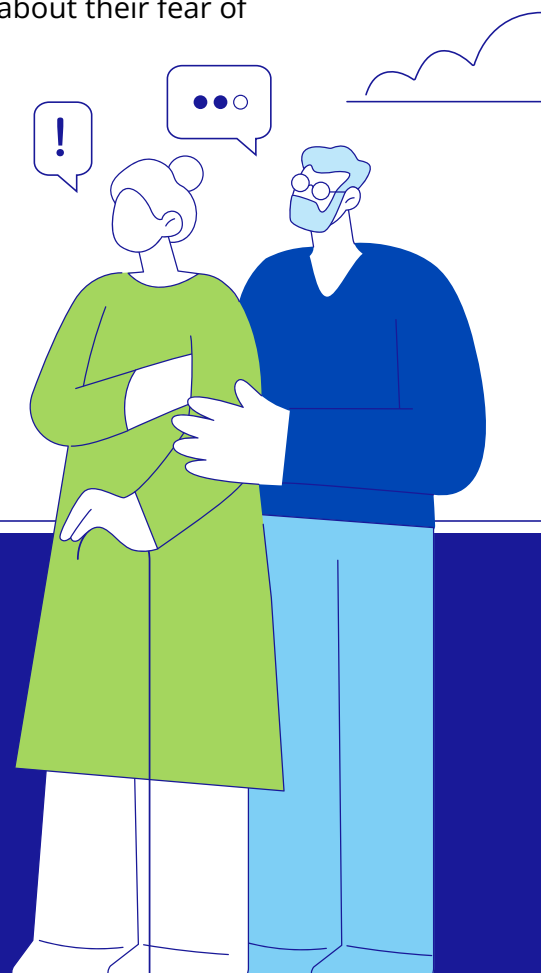
- Being aware of their rights, and knowing retaliation is never acceptable.
- Building positive relationships with the facility administration and staff.
- Talking with other residents and families in the facility who may be experiencing similar issues or problems.

- Sharing concerns and experiences with trusted staff or others who can offer support.
- Voicing concerns at resident and family council meetings where members can advocate for change together.
- Using the facility's grievance process. Every nursing home must have a grievance process and a grievance official. The facility must provide this information to each resident. When a resident files a grievance the nursing home must provide a written summary of its investigation and the results, including any corrective action to be taken because of the grievance. Nursing home regulations specifically state residents have the right to voice grievances without discrimination or reprisal – in other words, without facing retaliation.
- Know where to go when retaliation is suspected or occurs.
  - If retaliation causes a resident's safety to be at risk or if it involves abuse that may be a potential crime, call 911 or the local police department.
  - Contact the Long-Term Care Ombudsman program, they advocate for individuals in long-term care and can assist with complaints. Find your Ombudsman program by visiting [theconsumervoice.org/get\\_help](https://theconsumervoice.org/get_help).
  - File a complaint with your State Licensing Agency. You can do this anonymously, however, the more details and information you can provide will assist with the investigation and response.

It is not a resident's responsibility to prevent retaliation, but when residents hesitate to speak up because of the fear of retaliation, circumstances are unlikely to change and the problems may continue. Strong, enforceable, and timely protections must be in place to increase the likelihood that residents will feel comfortable and safe enough to file a complaint about their fear of retaliation, threats of retaliation, and actual retaliation.

**“Speak out – I know it’s scary, but find the Resident Council president, or another resident that seems to have somebody’s ear ... sympathetic staff members. If they get enough residents and staff together, that can confront a problem that exists for everybody. The staff don’t like when residents are having problems, because it makes their job harder. And you can call your ombudsman.”**

*– Rich, resident, Connecticut*



This document was completed for the National Center on Elder Abuse in partnership with The Consumer Voice for Quality Long-Term Care, and is supported in part by a grant (90ABRC0002) from the Administration on Aging, U.S. Department of Health and Human Services (HHS). Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official Administration on Aging or HHS policy. LAST DOCUMENT REVISION: MAY 2024