

# Advocating for Yourself

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## Why self-advocate?

- You can explain your needs better than anyone else.
- You know the situation better than anyone else.
- You can advocate to make your life better.



## Why people don't self-advocate

- Don't want to be a bother
  - Staff are there to work for you.
- Not worth the time
  - Let the ombudsman know
- Won't do any good
  - Won't know until you try
  - Creating documentation
- Fear of retaliation
  - Most issues won't lead to retaliation.
  - Retaliation is illegal

## Inhouse routes of self-advocacy



## Talk with Staff

- Fastest route
- Best for in-the-moment issues
- Speak directly with the staff involved
- Document who, what, when, and their response.

## Talk with supervisors

- Unit coordinator, Director of Nursing (DON), Social Services, Administrator
- Response should be quick
- Use to address
  - Ongoing problems
  - Unresponsive staff
  - Disrespectful staff
  - Abuse and neglect situations
  - Issues involving a different shift
- Document who, what, when, and their response.



## File a Grievance

- All nursing homes are required to have a grievance procedure.
  - [Federal Regulations on Grievances: 42 CFR § 483.10\(j\)](#)
- Response timeframes vary, but a response within a week is usually reasonable.
- Facilities must allow those filing a grievance to remain anonymous.
- Filing a grievance creates written record of the issue.
- The facility must provide a written response.
- During an annual survey, a sample of the grievances are reviewed by IDPH surveyors.
- This is a formal process, to the facility must keep records of grievances that have been filed for a minimum of 3 years.
- Grievance Factsheet in the chat box

## Resident Council

- This is a monthly meeting for nursing home residents
  - If residents want to form a council, other facility types are required to allow residents to form a council.
  - Guests allowed at consent of the residents
  - Facility must appoint a staff liaison
- Discuss and confirm concerns
- Written Minutes
- Minutes read at next meeting.
- A sample of the minutes is reviewed during the annual survey



## Care Plan

- The care plan is almost like a care contract with the facility
- It lays out medical needs AND personal preferences.
- Care plan meetings to discuss the written plan are held on admission then every 90 days
- The meetings can also be held upon request or after a change in condition
- If needed, the written plan can be modified between meetings.
- The care plan meeting must be accessible to resident and POA.
- You should always get a copy of the care plan.

## Ask Questions

- Clarify terms and concerns
- Ask questions about the care plan
- Ask for records
- Ask questions about the records.
  - Vague entries



## Outside routes of self-advocacy

### Ombudsman

- Resident directed, person-centered advocates
- Confidential
- Can give advice on how to resolve issues
- Facilitate communication
- Discretely investigate concerns
- Document outside of the facility



## Licensing and Regulatory Agency

- Usually the Illinois Department of Public Health
  - See [Facility Types where to File a Complaint](#)
- Best for chronic or serious concerns
- Facility staff are required to report some issues.
- Phone, fax, email, snail mail.
  - Written complaints are best
- Most complaints are investigated within 30 days, depending on the severity.
- Can be anonymous.
- “Valid” complaints can lead to change.
- Creates a record outside of the facility.

## Document, document, document

- In order for a complaint to be validated, the surveyor must have enough facts to show the facility was not fully in compliance with state and federal regulations.
- Keeping records helps focus the complaint, gives guidance on where to go and what to look for.
- Documentation helps you build your case
- It will support the facts - who, what, when, and where



## What to Include in the Complaint

- Resident name(s)
- Facility name and address
- Name and contact info of any witnesses
- Name of employees involved
- Important date(s)
- State specific allegations
  - (e.g. abuse, acquired infection, medication error, failure to allow compassionate care visitation, failure to respond to request for assistance, etc.)
- When did the incident occur?
  - Date/time
- Where did the incident occur?
- How was the resident harmed?
- How was the complaint addressed by the facility?

## Illinois Caregivers 4 Compromise

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**WE SUPPORT AND ADVOCATE FOR ESSENTIAL &  
COMPASSIONATE CARE AND VISITATION.**

**WHILE USING A SAFE AND REASONABLE PRECAUTIONS**



# FACEBOOK

**ILLINOIS CAREGIVERS FOR COMPROMISE-  
because isolation kills too**

<https://www.facebook.com/groups/illinoiscaregiversforcompromise>

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## ILLINOIS CAREGIVERS 4 COMPROMISE



<https://www.youtube.com/channel/UCiR3UNN0mgRDMMIDofUU4ow>

# ZOOM MEETINGS

We host a weekly zoom meeting on Thursday the 1st & 3rd & 5th Thursday of the month at 9 am. The 2nd and 4th Thursday they are at 7 pm. These meeting provide both information on the latest guidance, and changes made in long-term care and support for the families.  
All of our Thursday zoom meeting us the same link.

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## ZOOM MEETING LINK

[HTTPS://US02WEB.ZOOM.US/J/81028654307](https://us02web.zoom.us/j/81028654307)

MEETING ID: 810 2865 4307 PASSWORD: ESSENTIAL



## Illinois Caregivers for Compromise E-Blast

<https://docs.google.com/forms/d/e/1FAIpQLScHqZ8pZAthFjiBPC633CGVMYFGqkHBpR3Ibdf5NJImLeFWig/viewform>

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## IMPORTANT TIPS

- Whenever possible communicate with your loved one's facility by email or text. Save all emails and text, you never know when you will need them.
  - The most important thing we can do is document.
  - If you have concerns about your loved one's care and need help with the facility the Ombudsman office is always where you want to start first.
  - It is yours and your loved ones right to file a complaint with the state if you have any unresolved issue. If your complaint comes back no violations found, don't give up. File a second complaint if needed or contact another agency for help.
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# RETALIATION

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Kelly Richards, State Long-Term Care Ombudsman  
April 27, 2021

Resident Rights and Empowerment [video](#)





## Retaliation

- Fear of Retaliation
  - Real
  - Perceived
- Definition
  - Negative action (or inaction) committed by staff in response to a complaint to the facility, Ombudsman program, or state survey agency.
- Talk to your Ombudsman

## From the State Operations Manual

Guidance on F600 - § 483.12 Freedom from Abuse, Neglect, and Exploitation

### **Staff to Resident Abuse of Any Type**

*Nursing homes have diverse populations including, among others, residents with dementia, mental disorders, intellectual disabilities, ethnic/cultural differences, speech/language challenges, and generational differences. When a nursing home accepts a resident for admission, the facility assumes the responsibility of ensuring the safety and well-being of the resident. It is the facility's responsibility to ensure that all staff are trained and are knowledgeable in how to react and respond appropriately to resident behavior. All staff are expected to be in control of their own behavior, are to behave professionally, and should appropriately understand how to work with the nursing home population. A facility cannot disown the acts of staff, since the facility relies on them to meet the Medicare and Medicaid requirements for participation by providing care in a safe environment. CMS does not consider striking a combative resident an appropriate response in any situation. It is also not acceptable for an employee to claim his/her action was "reflexive" or a "knee-jerk reaction" and was not intended to cause harm. Retaliation by staff is abuse, regardless of whether harm was intended, and must be cited.*



## Examples of Retaliation

### Subtle Instances

- Call lights not answered or delayed in being answered
- Staff ignoring resident requests for help
- Staff withholding pain medication or are late when distributing medication

### Obvious Instances

- Rough care
- Abusive treatment
- Eviction or threatening discharge
- Withholding food or water

## What to do if retaliation occurs?

- Speak Up!
- Document the facts.
  - Who, What, When, and Where?
  - How were you affected?
- Contact your Ombudsman
- Consider talking to the Administrator
  - If the retaliation was done by someone other than the Administrator, make sure he or she is aware of the retaliation
- Consider filing a complaint with IDPH



## Questions and Answers

Please enter your questions in the chat