

Residents' Rights: Your Life, Your Care, Your Choices

Overview

This presentation provides information, tips, and resources for knowing and exercising residents' rights.

Facts

- Residents of nursing homes have rights in addition to rights as US citizen or resident.
- This additional set of rights, called Residents' Rights, is legally protected by federal law.
- The nursing home must protect and promote all of your rights.
- Exercising your rights can help ensure you have the quality of care and life you want and need.

Consider These Situations

- You like to stay up late and get up mid-morning. Staff tell you that if you want to have breakfast, you must be in the dining room by 8 AM.
- Staff ask for your input on your plan of care, but your only means of communicating is to move your head. You have more to share, but can't without proper support.
- Your nursing home has a weekly church service open to all residents. You ask the staff about inviting a rabbi to lead a service and are told "no."
- Can anything be done? "Yes!" Residents' Rights give you the right to have your needs met and your preferences respected.

Residents' Rights Have Impact

- Knowing and exercising your rights enhances quality of life and care through:
 - Dignity
 - Self-Determination
 - Choices
 - Information
 - Communication and access to persons and services inside and outside the nursing home

Residents' Rights Empower and Recognize You

- Residents' Rights put you in the driver's seat to choose, participate, receive information, and make decisions about all aspects of your care and life.
- Congress created residents' rights in recognition of:
 - The power imbalance between residents and staff; and
 - The tendency of nursing homes to operate as an impersonal system which required residents to fit-in.

Overview of Residents' Rights¹

1) Right to Exercise Rights

- As a resident of the facility and as a citizen of the United States
- Without interference, coercion, discrimination, or retaliation.

¹ See 42 CFR §483 for a full listing of Residents' Rights. Many state also have residents' rights laws or regulations which give additional rights to residents.

2) Right to Dignity

- Equal access to quality care, regardless of diagnosis, severity of condition, or payment source
- Be treated with consideration, respect, and dignity, recognizing each resident's individuality
- Freedom from abuse, neglect, misappropriation of property, and exploitation
- Freedom from physical or chemical restraints imposed for purposes of staff discipline or convenience and not required to treat medical symptoms
- A safe, clean, comfortable, and homelike environment, with the right to use personal belongings to the extent possible
- Security of possessions

3) Right to Choices

- You have the right to choices about care
 - Help develop your own care plan
 - Ask for care plan meetings and choose who attends
 - Choose your own doctors and specialists
 - Refuse or stop treatment or medication
 - Be free of physical and chemical restraints
- You have the right to choices about personal space
 - A safe environment with personal belongings, where possible
 - Easy access to the call light
 - Furniture and equipment that is functional for your needs
 - Share a room with another consenting resident
- You have the right to choices about lifestyle
 - Make choices about your schedule, personal care, and activities
 - Designate or revoke a surrogate decision-maker
 - Organize or participate in family or resident groups in the facility

4) Right to be Informed

- You have the right to be fully informed of
 - Risks and benefits of proposed care, treatment, and treatment alternatives
 - Changes to the plan of care
 - Changes in medical or health status
 - Notices in a language and format you understand (Spanish and Braille, for example).
 - Access to personal and medical records
 - Contact information for your physician, specialists, and all relevant agencies, including the state regulatory agency and the Long-Term Care Ombudsman Program

5) Right to Access

- Access people, services, and activities inside and outside the facility
- Have visitors you want, at any time you choose
- See your doctor, specialists, or representatives of the state survey agency or Long-Term Care Ombudsman Program
- Participate in social, religious, and community activities inside and outside the facility

6) Right to Manage Finances

- Manage your financial affairs

- Receive financial statements and information about services and charges
- Have excess personal funds deposited in a separate interest-bearing account

7) Right to Privacy

- Privacy in communication – oral, written, or electronic, with any person of your choice
- In personal, financial, or medical affairs
- During treatment and care of your personal needs

8) Right to Make Complaints

- Make complaints to the facility
- Ask staff to take steps to resolve complaints
- Make complaints to outside agencies – like the state survey agency or the Long-Term Care Ombudsman Program

9) Right to Remain

- You have the right to stay in the facility unless specific conditions are met, such as transfer or discharge is necessary for your health and safety or the health and safety of others.
- You have the right to
 - Appeal your discharge notice and remain in the facility until the appeal is decided;
 - Receive a 30-day written notice of discharge that includes information like the reason for discharge, the date of discharge, the location to which you will be discharged, your rights, and name and contact information for the Long-Term Care Ombudsman Program and the Protection and Advocacy Program (for residents with intellectual or developmental disabilities or mental health needs);
 - Preparation and orientation to ensure a safe and orderly discharge; and,
 - Notice of your right to return to the facility after a hospital stay or therapeutic leave, including bed hold policies, and a statement of your right to return to the same bed (if available) or the first available bed.

Are There Limits?

- You can exercise your rights as long as they don't infringe upon the rights of others.

Tips for Exercising Residents' Rights

- As a general principle, you have the right to choose aspects of your life that are important to you.
- You have the right to make choices about things like your schedule, visitors, and medical decisions.
- Think about these rights when you encounter situations you have an issue within the facility
- For example:
 - You need more information or advice from a third party to make a decision.
 - You are not given a choice like a requirement to see a certain doctor, or required meal times and locations.
 - You are told there is a certain policy for all residents. For example, one shower per week, or no visitors after 8pm.
- An advocate can help you with your rights. Get to know the Long-Term Care Ombudsman program.
- The Long-Term Care Ombudsman Program advocates for changes to improve quality of life and care for residents.

- If you are unsure of whether you have a right, ask staff for a copy of your rights, or talk to an Ombudsman Program representative.
- Invite an Ombudsman Program representative to the next Resident Council meeting.

What is the Nursing Home Required to Do?

- Post information about residents' rights, explain them, and give residents a copy in a language and format they can understand.
- Protect and promote the rights of the resident.
- Ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.
- Treat each resident with respect and dignity.
- Care for each resident in a manner and environment that maintains or enhances the resident's quality of life, according to the resident.

In a Nursing Home That Promotes Rights...

- Residents, surrogate decision-makers, and staff know residents' rights.
- Staff assist residents in exercising their rights.
- Staff know the residents as people, such as knowing their needs, preferences, and natural rhythms.
- Alternate modes of communicating are used with residents who, for example, are non-English speaking or have hearing or visual impairments.
- Information and choices are provided.
- A diversity of food and activities are offered.
- Person-centered care is practiced as a way of life.
- Staff and residents treat each other with dignity and respect.
- Staff and residents are happier.

Tips for Surrogate Decision-Makers

- A resident can choose a person to act on the resident's behalf and exercise his or her rights.
- Surrogate decision-makers include:
 - Resident representatives
 - Agents with powers of attorney
 - Agents with durable powers of attorney
 - Guardians
- In addition to tips for residents...
 - Get input. Discuss with the resident what he or she needs and prefers.
 - If the resident is cognitively unable to give input, rely on your knowledge of the resident and what he or she would need and prefers.
 - Only if needs and preferences are unattainable, base your decision on "the best interests of the person."
 - Remember, whenever possible, do what the resident would have wanted, not what you personally would choose.

If your rights are not being protected or promoted...

- Speak to a trusted friend, family member, staff member, or Ombudsman Program representative.
- Identify which right is being violated.
- Decide if and how you will address the situation, for example:

- Meet with the right staff person (for example, social worker, administrator, or director of nursing)
- Raise the issue at a resident council meeting.
- Make a complaint to your state licensing and certification agency and/or your Long-Term Care Ombudsman Program.
- If you make a complaint to your Ombudsman Program representative, he or she will...
 - Listen to and support you
 - Provide helpful information
 - Work with you to resolve the issue
 - Keep your conversations confidential
 - Only act with your permission

What About Retaliation?

- There are strict federal and state laws prohibiting acts of retaliation for voicing grievances and making complaints.
- Let your Ombudsman representative know when you have spoken up.

Residents' Rights Quiz

- True or false...
 - You must follow doctor's orders.
 - When you are in a nursing home, you must eat at the meal times set by staff, even if breakfast is at 8am and you would never eat that early.
 - You must communicate your input to the facility using only written or oral communications, even if you can only communicate through motion.
 - Your only choice of religious activity is the weekly church service at the nursing home, even if it is not affiliated with your religion.
 - A resident only can use the facility's grievance process to resolve a problem.
- You must follow doctor's orders.
 - False. You have the right to make decisions about your care and treatment.
 - The resident has the right to be fully informed and to make decisions in all aspects of his/her life that are significant to him or her.
 - Residents must be informed of the risks and benefits of any care, treatments, or orders, and he or she has the right to refuse.
- You must eat at the meal times set by staff
 - False. You can eat at your desired meal times, even if they are different from the scheduled meal.
 - Residents have the right to make choices about their schedule, including meal times.
- You must communicate your input using only written or oral communications
 - False. The facility must take your input into consideration and provide any support or assistance you need to communicate your input.
 - Residents have the right to information and communications in a language and format they understand.
- Your only choice of religious activity is the weekly church service.
 - False. You can practice the religion of your choosing, regardless of the facility's scheduled religious services.
 - Residents have the right to freely practice their own religion, can attend religious services outside the facility, and can have visitors at any time, including clergy.
- A resident can only use the facility's grievance process to resolve a problem.

- False. The facility must investigate and respond to any grievances filed by a resident, including letting them know how the problem will be resolved.
- Residents can file a grievance with the facility, make a complaint to the state licensing and survey agency and/or the Long-Term Care Ombudsman Program.

RESOURCES

- **The National Long-Term Care Ombudsman Resource Center (NORC):** <http://ltombudsman.org/>
 - **NORC Nursing Homes page-** <http://ltombudsman.org/nursing-homes>
 - **NORC Federal Nursing Home Regulations page-** http://ltombudsman.org/library/fed_laws/federal-nursing-home-regulations
 - **Locate and Learn about the Long-Term Care Ombudsman Program:** http://theconsumervoice.org/get_help

- **The National Consumer Voice for Quality Long-Term Care (Consumer Voice)** www.theconsumervoice.org
 - **Consumer Voice Nursing Home Residents page-** <http://theconsumervoice.org/issues/recipients/nursing-home-residents>