



— THE RESIDENT ADVOCATE —

The Resident Advocate - a newsletter for residents of long-term care facilities containing news and information on rights and care issues, plus updates on national policy. Please share with your neighbor when you've finished reading this issue!

Upcoming Events

May

- Older Americans Month

June

- World Elder Abuse Awareness Day (WEAAD) is June 15th

Residents' Rights Month 2019



October is "Residents' Rights Month," an annual event to honor residents living in all long-term care facilities. It is a chance to celebrate awareness of dignity, respect, and the rights of each resident. This year's theme, "Stand for Quality," emphasizes the importance of quality in all aspects of residents' experiences – quality care, quality of life, quality services, and quality choices – to name a few.

Excerpts from: An Address on Rights and Empowerment

Penelope Ann Shaw, PhD

Penny Shaw has been living in a nursing home for 17 years. She is a nationally recognized public elder, nursing home and disability advocate and activist. In October 2018, she gave a keynote address on rights and empowerment at the Annual Conference of the National Consumer Voice for Quality Long-Term Care, Resident Empowerment Luncheon. Below are excerpts from her remarks. For the full text of the address, go to <https://theconsumervoice.org/issues/recipients>.

Federal law guarantees you the right to self-determination – to make decisions regarding your life and care. This gives you the right to exercise control, to make your own choices, to be your own persons, to plan and create the life you want. It is you who is best qualified to make decisions about yourself. By law, your care and life must be individualized. You have the right to choose how you live, so you can attain your highest practical level of well-being. Self-determination is a right, not a special privilege.

Legal words gain force in the real world by your becoming empowered, learning how to advocate for yourselves, getting staff in your facility to know what you want.

Your staff are good people for the most part, but they might resist your choices. Some are frantic at the idea you might make bad decisions. They have a lot of work to do and they often need more help than they have. Giving you what you want is not spoiling you. Your insisting about what you want is not a behavior.

You have the right to ask CNAs to do your routine the way you want. Providing care in an institutional task-oriented way – wash, dress, feed – is not person-centered care. Each resident is unique and we have the right to our preferences. Despite some CNAs having had years of experience, they lack the lived experience of being a resident, which makes you the expert in your care. When there are differences of opinion [in how my care is provided or what I should do], I explain my rights and am firm. I have had their supervisor talk to them if necessary. Enhanced training on person-centered care may be useful.

I also develop positive working relationships with CNAs, as good communication is essential. I show appreciation for the work they do and acknowledge the problems of their jobs. This helps create an alliance – a collaborative relationship.

Your right to self-determination allows you to speak directly to staff in all departments – dietary, social work, maintenance, housekeeping, administration. Tell staff what you want, what you need. You can make choices about every aspect of your daily life.

Here are some examples of choices I personally have made:

- I orient nurses and CNA's new to my care routine myself.
- I manage my own medical care by having discontinued medications I didn't need, by having chosen an outpatient primary care physician, and by scheduling my own outpatient medical and dental appointments and transportation.
- I ask maintenance for what I need – like choosing the light and temperature in my room, and having a lock put on my closet door, as CNAs were putting my clothes on my roommate.

With administration, I email them my requests. I have been successful in getting what I want by researching and documenting, to show how what I want is either a resident right or a medical need. If there are policies with no basis in law, I just refuse to comply.

How did I become this empowered to advocate for myself? I learned my rights.

How do I suggest you get your own choices? Know your rights. You have the same rights as anyone living outside a facility. Feel confident that your needs and concerns are important. Be a self-advocate. Self-advocacy is essential in asserting your rights and getting your needs met. Speak up about both what your rights are, and what's important to you! No dream is too large.

Remember you have the experience and expertise of yourself. You are the expert. Be engaged. Take chances. Experiment. Ignore the pushback. Have high expectations. You can succeed. You can find solutions. You can change opinions and influence decisions. You can get your needs met. You have the power.

The rewards for asserting your rights will be life-changing – feeling stronger, providing you with a dignified existence and respect, being independent, receiving self-directed care, maximizing your quality of life, increasing your self-esteem, becoming empowered, being more satisfied and happier, thriving not just surviving.

You don't have to make this journey alone. You have no greater champions than the staff at the Consumer Voice, ombudsmen, and other resident advocates across the country. They can educate you about your rights and strategies. They can train you with the tools to be self-advocates. They will inspire and support you, so you can advocate for yourselves. They can help you find your voice, if you feel voiceless.

I urge you to join with me in this revolution of empowerment, to work toward transforming nursing homes in this country. We can realize the promise of control over our lives. You can help be the solution and benefit other residents.

To contact the Consumer Voice or find an ombudsman or advocate in your area, call 202-332-2275, or email info@theconsumervoice.org.



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