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An Address on Rights and Empowerment
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I introduce myself as someone who has been living in a nursing home resident for 16 years, due to functional limitations from a rare disease. I need assistance being washed, dressed, groomed, positioned and transferred. I can use my arms and hands to feed myself, use a computer and drive an electric wheelchair. I do not consider myself institutionalized, but rather community-dwelling. My facility is not a prison, it is only where I live. It is my home. My facility does not define me as I go out into the larger community every day, weather permitting, to do my work as a local, state and national public elder, nursing home and disability advocate and activist. I often speak out for those of you who are seldom thought about, much less seen or heard.

I address my talk today to everyone - residents, family members, advocates, all resident representatives. But for brevity's sake, I will collectively address you residents. I want to talk to you about your rights and your becoming empowered. Federal law guarantees you the right to self-determination - to make decisions regarding your care and life. This is a fundamental human right to freedom and autonomy. 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. Remember it is you yourself who is best qualified to make decisions about yourself. By law, your care and your life must be individualized. One-size does not fit all. Therefore, you have the right to choose how you live, so you can attain your highest practical level of physical, mental and psychosocial well-being. This right to self-determination is a right, not a special privilege.

How do legal words on paper gain force in the real world? It happens by your becoming empowered, learning how to self-advocate for yourselves, getting staff in your facility to know what you want. I tell you up front that this can be a difficult journey, like a road trip in a steep mountainous area - full of switchbacks and blind spots. You might feel lost. It would be tough to feel lost. Fortify yourself. As it is difficult to go it alone, it can be useful to have a professional driver to be your navigator. I will talk more about who can guide you later.

I take a bicultural view - your staff are good people for the most part, but it is your staff who might resist your choices. Nurses are in the business of caring, and some old-school nurses are frantic at the idea you might make bad decisions about your schedule and food. Nurses are concerned you might want to spend too much time in bed, or that you might want to eat unhealthy food, especially if you are diabetic. I read in a professional journal what some nurses said. They said - "Do we give them everything they want? Where is the line?" "When do we stop?" "We need to do what's best for them." Staff also often put their own needs first, because they have a lot of work to

do, and they often need more help than they have. Some nurses are more empathic and more flexible than others. Those that aren't can be controlling, bossy, and give you trouble. Giving you what you want is not spoiling you. Your insisting about what you want is not a behavior. These perspectives of person-centeredness are obsolete.

I spend more time with CNAs, as CNAs are the ones who provide most of my direct care. You have the right to ask them to do your routine the way you want. They may have been trained in an institutional task-oriented way - like in a factory where efficiency matters - wash dress, feed. This is a corporate model, not person-centered care. Some CNAs don't acknowledge that each resident is unique, and that we have the right to our preferences. They don't see the person who you are. Some are defensive about accepting direction as they feel they are the experts, having had years of experience. But they lack the **lived** experience of being a resident which makes you the expert in your care. I personally use the Personal Care Attendant model of the disability community. I choose my own CNAs, train them, and if I don't like the care they provide, I refuse to be on their assignment.

CNAs' personal qualities may explain their resistance in part. Some are naturally person-centered, open, kind, able to listen and respond, seeing your individuality - saying something like "Just walk me through your routine." Others are resistant to residents' directing their own care and have poor attitudes - with a could-care-less style, or deflecting you with words like "You don't really need it." They may act like the work is beneath them, unprofessional, failing to understand the concept of customer service, argumentative. I discovered these reactions could be for many reasons including - feeling they don't need to be told what to do, or feeling they don't have any rights. As more than one CNA has told me. "You have rights, but we don't have any rights."

When CNAs resist my direction one approach is to figure out their personalities, so I can work with them. When there are differences in opinion, I explain my rights, and am firm. I do not let them tell me what to do. Sometimes I just say no. 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 for me. I acknowledge the problems of their jobs - how hard and exhausting it is, that there are not enough staff, their low-wages, or that they are having a bad day. These comments help create an alliance - a collaborative partnership. I consider this person-centered care in reverse, when I figure out what CNAs' needs are. Then, when I help them get their needs met, they in turn will help me get mine met.

Your right to self-determination allows you to speak directly to staff in all departments - dietary, housekeeping, social work, maintenance, housekeeping, administration. These staff might want to interview you about your personal preferences. That would be a top-down process, possibly paternalistic. The opposite is the way it should be done. It is **you** who should approach staff with your requests. **Tell** them what you want, what

you need. Do not limit your requests to your schedule, the food you want to eat, and what activities you'd like to do. 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 CNAs new to my care routine myself'.
- I ask for extras - putting away my purchases from shopping, giving me books and my cord to charge my cellphone, organizing my clothes in my closet, picking up things I drop on the floor.
- I have my electric wheelchair charged in my room, as CNAs were not charging it properly when I could not see them do it.
- 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.
- I call cooks directly to order my meals. I sometimes ask them to prepare me something that is not on the menu.
- I have my mail held at our reception desk, as it was being lost.
- I pick up my own supplies at central supply, as they were not always available on my unit, when I needed them.

Once, there was no one on my unit willing to push my power chair into my room manually as I require, and then engage the battery charger properly. So, I went to the Fire Station near where I live, and asked for assistance. A lieutenant, and two of her firefighters, came to my facility and provided the care for my chair the way I wanted it done. I'm not suggesting you do the same. I'm only sharing with you, that I will do whatever is necessary to get my needs met.

As for administration, it's best if they are supportive. In practical terms with mine, 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. And, if there are policies with no basis in law, I just refuse to comply, as with the one asking residents to sign out and back into the building.

I hope you can see that I live a very self-directed life.

How did I become this empowered to advocate for myself in my facility? From nursing home advocates, I learned my rights. I do believe, however, that my actual strength comes from being a disability advocate and activist. I use disability community thinking. We too have strong laws and regulations - in particular the Americans with Disabilities Act. The disability advocacy community is large, organized, assertive, resilient. In 2015, I confronted the mayor of my town at a meeting of Town Council,

when he had denied us persons with disabilities in town our rights. I got us an American with Disabilities Act coordinator. Now in 2018, I am a plaintiff in a federal ADA lawsuit against my town for failure to fully comply with ADA requirements. These include sidewalk clearance, safe curb cuts, accessible playgrounds and library internet access for individuals with low vision. You can see that I confront those who would deny us our legal rights.

I also have had the privilege of being in the Boston Globe several times - twice on the front page - as a public advocate challenging state policies for both accessible transportation, and for requiring a photo ID to enter our State House office building. I enjoy being bold. With the skills and disability ways of thinking I have built as a disability advocate, I have become confident to fight for my rights in my nursing home as well.

How do I suggest that **you** get **your** own choices? Know your rights. You have the same right as anyone living outside a facility - to choose the lifestyles and conditions for your everyday life. 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 that 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. Avoid tokenism. Try to get everything you want. You are not helpless. You have the power. Power is there for the taking. No dream is too big.

The rewards for asserting your rights will be life-changing - feeling stronger, providing you with a dignified existence and respect, being independent, receiving the self-directed care you want, maximizing your quality of life, increasing your self-worth and self-esteem, becoming personally 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 National Consumer Voice for Quality Long Term Care, ombudsmen, and other resident advocates across the country. They can assist you navigate up the mountain by being your mentors. They can educate you about your legal rights, regulations 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.

These resident advocates will also continue to advance, and see enforced, federal regulations providing for resident-centeredness in care and life. They will work to hold corporate owners and administrations of your facilities accountable.

In closing, I tell you that I feel honored to have had the opportunity to address you today. I urge you to join me in this revolution of empowerment, to work toward transforming nursing homes in this country. In this way, we can realize the promise of primary control over our lives. As an active participant, you can help be the solution and benefit other residents. Think about what President Barack Obama said - "**We** are the change that we seek."

Thank you for listening.