

Understanding When To Ask For Help

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November is National COPD Awareness Month – something that’s caused me to reflect on my learning about disability, services, needs and when to ask for help.

I hope you’ll allow me to share my experience with you. Someone close to me – let’s call them Jean – had Chronic Obstructive Pulmonary Disease (COPD) which the Center for Disease Control (CDC) defines as “a group of diseases that cause airflow blockage and breathing-related problems.” This includes emphysema and chronic bronchitis and affects nearly 16 million Americans.

Over time the COPD, along with other disabilities and health issues, became more serious and required more care. The issue was, no one knew what to expect or who, beyond the doctor, could be trusted for advice and assistance.

As issues advanced, we were not exactly sure what was the best way to accommodate Jean. The thing that was certain was that Jean wanted to be in her home and not a hospital or nursing home. Jean now required a wheelchair to get around and oxygen use on nearly a 24/7 basis.

Where do we get a wheelchair? Which is better? Is an additional cushion needed? Should we get a stair lift? Do we renovate the shower to be a walk-in? Is this covered by insurance? How much? There were lots of questions that often led to more questions.

Eventually, Jean had a hospital stay followed by a stay in a nursing home. More questions arose. Does my insurance cover this stay? How long? Is there supplemental insurance? What happens if I switch facilities? What happens when I go home? Each facility wanted to send Jean to another, but Jean just wanted to go home. The situation was very confusing for everyone and no one was sure who would be able to help or who could answer what seemed like common questions where internet searches led to even more questions.

I am sharing this with you to let you know that there are people who can help. There are organizations that specialize in assisting with situations like this. Some may be narrowly focused organizations, others may be Independent Living Centers like CIDNY. They’re here to help. All you have to do is ask.

But first you need to know they exist. There are specific programs statewide that can help. In NYC, the Long Term Care Ombudsman Program can help people and families advocate for themselves when dealing with nursing homes. The Open Doors program can help people transition back into the community. Help is out there.

People deal with many unknowns, especially related to health care and caring for their loved ones. You don’t have to do it alone. Organizations like CIDNY exist to help you. We know you have questions. We know it can be confusing. At CIDNY, we have the history and experience to answer your questions, and if we can’t directly assist you, we’ll be sure to refer you to someone or someplace that can.

Need help? Have a comment? Email us at info@cidny.org.