

## ***How My Mind Helps Me Thrive***

[Disability Issues](#) (Vol. 45, No. 2, Spring 2025)

By Penelope Ann Shaw

*Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes.*



Twenty-four years ago, I became unexpectedly disabled. I was on life support and not expected to live – but I did. It left me with physical limitations that prevent me from standing, walking, washing or dressing myself, cooking or cleaning. I also have no fine motor skills. For example, I need scissors to open an envelope, I use a power wheelchair, and I'm unable to drive a car.

Because of these changes, I am more aware of the many ways my mind benefits me. I notice how often I journey inward to a different world where I have incredible skills. In this world, I have the ability to plan, analyze, make decisions, remember, reflect, observe, organize, recognize people, identify patterns and make sense of them.

It's a place where I think creatively, synthesize, reason, communicate, evaluate information and experiences. All these abilities have practical applications, such as, they help me manage daily tasks, to focus my attention on something and ponder it. They help me to process different types of information, gaze inward at visual pictures, recognize sounds, distinguish colors, imagine new opportunities.

With my mind, I can process and interpret physical sensations like being hot, cold, in pain or fatigued as well as emotional sensations like being relaxed, pleased, concerned, frustrated, disappointed, determined. I use all my senses; not only visual, but also hearing, touch and smell. When I'm under pressure or feeling overly taxed or frustrated, I often cope with my worrisome thoughts by escaping into my mind. There, I gain new perspectives by quieting my thoughts and having an inner conversation with myself. I emerge feeling revitalized and more optimistic.

With visual perception and spatial awareness, I scan the environment to judge the distance and speed of vehicles crossing streets in front of me. If necessary, I can then stop to be safe before proceeding. Thus, I can simultaneously focus on driving my wheelchair and checking out my surroundings.

I am a curious person. I read the latest local, national and international news to learn about the world I live in and try to make sense of what is going on in it. When reading, I am inspired by new ideas and insights that provide useful points I want to make in pieces I'm writing. When

editing the piece, my mind also triggers other ideas. In addition to finding intellectual tasks interesting and illuminating, they are also intellectually stimulating and rewarding. Coming up with new ideas is like being on a journey and traveling to a new country. Something I can no longer do in person.

Decision-making skills are essential to my well-being. I rely on them to solve problems and navigate hardships, which helps me feel more peaceful. Thinking things through is like consulting with and being supported by another person—my inner voice of guidance. I often talk through an issue in my mind and then decide how best to approach it based on the strategies I develop and evaluate. Sometimes, this process even includes an imagined conversation with the person I hope to influence.

With my language capabilities of French and some Spanish, I'm able to communicate with staff from various countries who work in my facility. Additionally, my skills with English as a Second Language, helps me communicate in English with staff who have limited proficiency.

I often let my mind wander freely and engage in daydreaming. For example, during the winter, I dream of summer and being outside, enjoying the warm weather. In this way, I look to the future. When I'm in bed at night, I often go to a quiet inner world where my cognitive functions stimulate me, keep me busy, and mitigate boredom. This internal space is my office with no interrupting distractions. In bed, I often read books, using a pen and paper to write down thoughts for what I'm writing and to plan my days. Later, when I am asleep, my mind rests in preparation for the next day's work. Due to my paralysis, having something satisfying to do in bed is especially important because once I'm in bed, I cannot get up myself. I'll be there until the aides get me up the next morning.

With my memory skills I store useful information and later retrieve what I need. With short-term memory, I can remember the name of a person I just met, a task I must complete or something I need to buy. With long-term memory, I can recall events from long ago, which I think I'd forgotten.

I can reflect on my personal history, replay events and reminisce about the passage of time by calling up both people and experiences. Reflections can also be purposeful, such as, knowing people's names, or recalling information I've read and studied. All my memories are internally organized for easy access. It is like having a personal library where everything has been catalogued. I am amazed at how large the storage area is!

Cognitive skills are especially useful when living in a nursing home. To get my care done right, I often need to figure out how to work with nursing assistants who have different personalities and skills. I also need to know how to inform, motivate and persuade the management of my facility to address the problems I encounter. With these skills, I survive institutional life. I would prefer home and community-based services, but I do not qualify for these since I'm a 2-person assist and require 24-hour access to care.

Overall, I am amazed by my mind. I'm in awe of the power of thought and all it offers me. Because of it, I feel stronger, more confident, and uplifted. Most importantly, through the workings of my mind, I transcend my limitations. My cognitive abilities, interior journeys, and inner life liberate me from the constraints of my disability. Providing me with a positive state of mind and a full life each day – something for which I am appreciative of.

In closing, I often ask myself – who could have predicted that when I was on life support and not expected to survive, I would one day thrive and live a full life thanks to my mind, my consciousness, my cognitive strengths and abilities that I benefit from every day?