



Sometimes when you least expect it, you have a learning experience that leaves a significant imprint in your life. This has happened to me on a number of occasions. The most significant event to date was when I sustained a serious leg injury that completely incapacitated me. I had spent my entire career providing care and advocating for others. I now found myself on the other side of the table. I was the one who needed help and had to practice what I preached.

As I lay in bed, thoughts of how I was going to manage my day to day affairs were rapidly building in my mind. You can easily get overwhelmed and anxious in trying to figure out the vast amount of details that need to be addressed. Job deadlines. Hand-offs to co-workers. Appointments. Events. Kid schedules. Managing personal affairs, such as paying bills, feeding your family, and caring for significant others or pets. The list was endless. When you're faced with a life-changing event, you really have to quiet your mind and get centered or you'll feel overwhelmed and stuck. You can pare down the details of any of your responsibilities though it helps to focus and begin with the basics. Here are a few things to consider when you're the one who needs help and it's time to be your own advocate.

KNOW THAT YOU'RE PART OF A TEAM

It's easy to forget that you are an important member of your own health team. Your ability to actively listen, communicate respectfully, cooperate and follow through with agreed upon recommendations, with consistent efforts to ask questions and stay informed all impact your care and recovery. When you begin to see yourself and participate as an active member of your medical/support team, it becomes easier to plan and be actively involved in decisions. Being open and willing to partner with others is an important step in advocating for yourself. This entails a conscious effort to "help others, help you" and can be done with a little foresight, planning, and communication.

GATHER INFORMATION & ASSESS YOUR NEEDS

Gathering key information so others know how to intervene on your behalf, is a good place to start. To prepare for my leg surgery, I updated my personal health record¹ along with my intentions for life-sustaining treatment². In the event of an unforeseen circumstance or change in my health, I wanted to be sure that there were no second guesses on what I wanted in terms of care. I also compiled a list of key contacts regarding our home assets, including passwords for all of my various online accounts. I talked with my family about this so all lines of communication were clear. It's difficult to think of these things when you're in a state of crisis. Because of this, it's best to address these topics, consult with appropriate professionals, and compile necessary documents before needs become urgent. Think of yourself as the captain of your ship. Take charge and own this important responsibility.

UNDERSTAND YOUR HEALTH PLAN

Take time to understand how your health insurance operates. Do this in advance of procedures to confirm specifics and avoid surprises. Know what services require pre-approval or referrals, the amount of co-payments and out-of-pocket limits, and coverage for various levels of care. A simple call to your insurance carrier can provide answers to these questions. Take time to activate your online insurance account so you have a quick reference in case you forget details. If you are employed, learn how long your insurance benefits continue if you do not return to work. Verify your benefits for short-term and/or long-term disability coverage, if you have this. In addition, have ready access to the phone number of your pharmacy so you can understand your medication prescription coverage. There may be opportunities to save on costs by ordering a three-month supply for ongoing prescriptions or by mail. If you utilize Social Security benefit programs and are unsure about your

coverage for medications, health and/or disability insurance, contact a representative from the Senior Health Insurance Assistance Program (SHIP)³ to clarify and provide details for you. It's helpful to include a trusted family member or friend in these discussions as another backup source of information. Insurance representatives, human resource departments, pharmacists, and other health providers are all members of your team. Developing partnerships with them will support you during various life transitions.

LEAD BY EXAMPLE

Instead of expecting others to anticipate your needs, relying on figuring things out as you go along, or denying that you need assistance or an accommodation, take the bull by the horns and investigate resources. Taking the lead to communicate your needs with significant others makes it easier for people to know how to pitch in. It also helps you take charge of your livelihood.

There's an array of non-profit and online health resource centers that can help you think through options and identify supportive resources.⁴ There are also non-profit agencies⁵ and private services⁶ that can help you discover resources for your particular situation. Take time to anticipate your needs and connect with others to expand your resource knowledge. This helps you devise a plan that supports your unique situation.

PROACTIVELY PARTNER WITH OTHERS

Advances in medicine and technology have created short windows of time to receive care. Hospital stays are short and outpatient same-day surgeries and procedures have become the norm. People naturally assume that once you are home everything is okay. On the contrary, your needs for extended recovery time and support require that you devise ways to enable your progress. This is why being proactive in partnering with others is key. Having access to immediate incidentals and support can help immensely. For example, on the day of discharge, having groceries on hand or precooked meals, someone to run and fill a prescription or help you to schedule prescribed services like a visiting nurse, therapist, or medical equipment can ease tensions and allow you to follow through in getting yourself established for the days ahead.

In my instance, I knew would not be able to climb stairs and I would have limited ability to walk for several months. Rather than sit complacently waiting for others to intervene, I partnered with my family, close friends, and faith circle to identify support and a game plan. Part of this involved some simple home modification that involved rearranging my living quarters. This included setting up a bed on the first floor, organizing easy to reach toiletries and supplies, placing a few hooks and grab bars in the bathroom, installing a hand-held shower nozzle, and locating a wheelchair through a medical equipment-loan closet to help with long-distance transports. I also made sure to have clothing that was easy to take on

and off to support my comfort and limited functioning. In addition, we moved my computer to the first floor so I could stay connected with family, friends, and work associates. All of these accommodations made it safer for me to get around and maximized my functional abilities.⁶ Outlining specifics made it easier for people to gauge their time and know how best to help. It also provided opportunities to build relationships.

Partnering with others to support my needs and create an accessible living space enabled me to follow through with care plans, stay positive, and engaged. Making this a priority and happen was huge. Without this I could have struggled and fallen prey to apathy, despair and isolation. I may have gone backwards instead of forward in regaining and retaining my independence.

PERSEVERE

Oftentimes, individuals and families are required to make decisions, transition, and adjust to change in ways that are faster than expected. This is why your active involvement to explore resources and identify your transition needs are so important. Staying focused on your end goal allows you to chart the course of your recovery and make progress. Communicate and show appreciation to your support team regularly so they can provide help from the get-go. If some people are slow to understand or provide support, take a deep breath, regroup, and persevere. You may need to assert yourself by explaining how all of these efforts will make it easier for everyone involved. Refrain from letting someone's lack of involvement hurt your feelings or derail your intentions. Move forward with a loving, can-do attitude.

Believe in your ability to take charge, partner with others, and move forward despite the challenges you face. Your capacity to learn and apply resource knowledge is far greater than you think. Being proactive can help you create and cultivate positive outcomes as you transition in life. The power to advocate for yourself starts from within. Embrace this ability and reap the benefits.

Kristine Cichowski provides educational and business consultation to small businesses and non-profit groups through her company, Power To Be. Kristine's work is based upon 30 years of experience in patient/family/professional education at the Rehabilitation Institute of Chicago (now known as the Shirley Ryan AbilityLab). Power To Be Empowerment Programs are designed to teach families and individuals how to effectively advocate for their loved one and themselves. To learn more, visit www.powertobe.net or call Kristine at 847.951.3365 to schedule a program for your management teams, employees, or members.



(1) Personal Health Record – Create Your Own, Shirley Ryan AbilityLab LIFE Center, <https://www.sralab.org/lifecenter/resources/personal-health-record-create-your-own>
(2) Illinois Department of Public Health, Advance Directives. <http://dph.illinois.gov/topics-services/health-care-regulation/nursing-homes/advance-directives>, (2) Aging with Dignity, Five Wishes. <https://agingwithdignity.org/five-wishes/about-five-wishes>, 1.888.5WISHES
(3) State Health Insurance Assistance Program (SHIP), <https://www.shiptacenter.org/>
Hotline: (877) 839-2675
(4) Age Options, <http://ageoptions.org>, (708) 383-0258
(5) Elderwerks, <http://www.Elderwerks.com>, (847) 462-0885
(6) NShore Patient Advocates, <http://www.northshoreRN.com>, (312) 788-2640
(6) AARP, Home Safety: How Well Does Your Home Meet Your Needs? http://assets.aarp.org/external_sites/caregiving/checklists/checklist_homeSafety.html