# STORIES FROM A NURSE ADVOCATE

by Anne Llewellyn, MS, BHA, RN, CRRN,  CCM, CMF, Nurse Advocate

# Welcome!

Welcome to my latest Special Report: *Stories from a Nurse Advocate*. I started writing my blog, Nurse Advocate, six years ago as I was recuperating from a life-changing illness. I had found a group of nurses on Facebook called Nurse Bloggers. I was intrigued by what the nurses were doing.

Over a period of weeks, I read many of the posts my colleagues put into their blogs. I thought it would be an interesting way for me to process what I had gone through. I also had several experiences from my cancer journey that I thought would be helpful for patients, caregivers, and members of the healthcare team. I was learning that blogging would allow me to share stories and educate in a non-threating manner.

One of the nurses in my group explained how to get started. She showed me how to develop a system for my posts that would allow me to write a post and share it with my connections and on social media. I also got help from my nephew and his girlfriend (now wife) with writing and editing. They gave me the confidence to write and share information that would be helpful.

My first post came out on July 10, 2015. The post told readers who I was and why I was writing a blog. I made a commitment to myself that I would write the blog weekly, and with the encouragement of readers and followers, I have kept my promise and have written a post almost every week since I started. To date, I have written well over 200 posts. I have hundreds of followers and their comments on posts keep me motivated to continue the blog.

The process has been cathartic and empowering. I typically write on topics that are personal or things that I see happening in my world as a nurse case manager/nurse advocate. I focus on sharing information that helps people (patients and caregivers) deal with challenges they find when they're thrust into the world of healthcare. I also try to reach healthcare providers to let them know how hard it is to be a patient in today's healthcare system. My goal is to use storytelling to educate and empower people.

Over the years, I have gotten great feedback. My examples help everyone involved know that by working together we can have a healthcare system that is safe, equitable, and meets the needs of patients, their caregivers, and all members of the healthcare team.

I decided to put this Special Report together to highlight posts that tell important stories on empowerment, patient engagement, care coordination, and resilience of the human spirit. Today, with healthcare in a disrupted state, helping people navigate the complex world of healthcare is where my journey has taken me.

I hope you will take time to read this special report and subscribe to my weekly blog posts. To learn more about what I am doing, visit my website, Nurse Advocate, at www.nursesadvocates.com. There you will find resources, conferences and speaking engagements I have lined up, and a variety of posts from my blog.

I look forward to your comments, questions, and recommendations for topics you would like to see covered.

Anne Llewellyn, MS, BHA, RN, CRRN, CCM, CMF
Nurse Advocate

allewellyn48@gmail.com

# Contents

**Welcome!** i

## Why I Write Nurse Advocate 1

**It takes more than luck** 2

Many people told me I was lucky to survive cancer. This post shows it wasn’t luck, but the conscious decisions I made along the way.

**The fear factor is never far away for patients** 5

I wrote this post when thought I was going to have a recurrence of my brain tumor. I shared my feelings and what that experience was like, but I also wrote it as a message to oncology teams so they realize patients need help when they hear, “Your cancer is back.”

**The joys of travel as a disabled person** 10

I wrote this post after my first trip as a newly disabled person to explain that travel is still possible and fun for those who are disabled. It was liberating to realize I could still travel and to share my story!

**What to do while waiting** 14

I wrote this post to share one of the most difficult things people who are patients or caregivers do—WAIT. It was eye opening to me how long people must wait in our healthcare system, and how common acts of courtesy can make the waiting bearable.

## Tips To Make Your Journey Successful 17

**10 tips: To prepare, reduce risk, and be smart** 18

This post shared how a life-changing experience changed my perspective on being prepared.

Who's Who in the Healthcare System 46

**Why are you involved?** 47

This post shows the importance of educating all members of the healthcare team as to the role, function, and value of having a nurse advocate involved in your care.

**Knowing who's who in the healthcare system** 49

This post reviews who's who in the confusing healthcare system. Patients and their families are the only constant members of the healthcare team, and they need to make sure they take an active role in the system.

**Care coordination: We can do better** 52

I recall an experience that made me realize we have a lot of work to do to help those with chronic medical conditions like diabetes live a healthy life.

**Appropriate use of health resources** 55

I wrote this to educate consumers on appropriate use of healthcare resources. There is data to show that when consumers are involved in their care, they make better decisions and costs are lower.

Why Everyone Needs a Patient Advocate 60

**It's the little things that matter** 61

A short story on how the little things matter to our patients and ourselves.

**Everyone needs an advocate when they're thrust into the complex world of healthcare** 63

A post about my own experience needing a caregiver and advocates.

**Advocacy around the world** 68

This post shows the emerging practice of patient advocacy, because healthcare is complicated wherever you live!

## Chapter 1

# Why I Write Nurse Advocate

# It takes more than luck

Many people told me I was lucky to survive cancer. This post shows it wasn't luck, but the conscious decisions I made along the way.

https://nursesadvocates.com/it-takes-more-than-luck

On November 24, 2014, I was diagnosed with a central nervous system lymphoma brain tumor. Having had no symptoms leading up to the diagnosis, I was shocked to learn my fate. After a year of strong chemo and close contact with my hematologist/oncologist, I was told I was lucky to be in remission—but that my tumor could recur so I would need regular MRIs over the next five years to catch a recurrence early.

I am fortunate to be alive today, as I was very sick and almost died from the brain tumor. It was not operable and was located on my brainstem. I don't remember a lot of the early days of my cancer journey; I rely on my husband to fill in the blanks. But today, I know it takes more than luck to fight cancer and come out on the other side. Here are some examples.

I was told I was lucky to be treated in a well-respected cancer center where I was diagnosed and treated by experts. Yet I would not have gotten to that hospital if it weren't for two friends—one, a nurse case manager, and the other, a social worker in the practice of patient advocacy.

When they heard I was sick, both came to see me and recognized I wasn't in the right hospital for my diagnosis. They asked my husband if they could do some research and get me moved to a more appropriate facility. They got to work and together decided on a plan of action. They called their contacts and found a neurosurgeon at the University of Miami who agreed to accept my case. I was discharged from the small community hospital and seen by the neurosurgeon a few days later. I was examined, admitted, and scheduled for a biopsy to determine the type of tumor that I had. Once the tumor type was known, the neurosurgeon referred me to a hematologist who specialized in the tumor I had.

Looking back, I view the intervention of my two friends who advocated for me as a key factor in saving my life. Today, I realize that everyone needs an advocate when they are thrust into the complex healthcare system because the current system is not set up for the patient—it is set up for the healthcare system to work just as it does.

I was told I was lucky to have had the type of tumor I did, instead of a glioma—a fast-growing tumor that is less responsive to treatment than the lymphoma I had. I was told I was lucky that my tumor responded to the chemotherapy prescribed.

But I was fortunate to receive the treatment that eradicated the tumor because of the work of my hematologist. We learned that he had dedicated his career to understanding lymphoma cancers after his mother died from that type. He is committed to finding treatments to fight these tumors.

I was told I was lucky to have good health insurance and a disability policy that allowed me to receive the care I needed. In reality, I had a good medical insurance policy because my former employer took the time to choose a policy that was comprehensive, provided a good network, and offered reasonable deductibles and an affordable premium. In addition, my employer had the foresight to offer a disability policy to their employees. This policy allowed me to have an income while I recuperated. As a result of these decisions, I did not have the financial burden many people face when they're diagnosed with a catastrophic or chronic disease.

I have been told I am lucky to have a wonderful husband who stood by my side, advocated for me, kept me safe, and supported me 100% during my cancer journey. I'm not sure this was luck, as we have worked hard to be there for each other in good times and in bad. In addition to my husband, I have supportive family, friends, and colleagues who prayed and helped us as we traveled through the journey. For all of these people, I am grateful.

I am not sure how much luck played into my journey. I genuinely believe my faith is my lucky charm, and my faith is stronger than ever. I truly believe I am here today because God was not ready for me; He still has plans for me! I pray every day to know what I am here to do.

Today, I am grateful I survived a severe health crisis that rocked my world. As a result of my journey, I have a new outlook on my life and the healthcare system I work in. I realize how hard it is to be a patient or a caregiver in today's complex healthcare system. I am doing what I can to raise awareness through my writing and speaking to educate and empower all to take an active role in their health and healthcare decisions. I also am working to ensure people know the role a patient advocate plays in helping them have a voice in their care.

Although I am not 100%, I am adjusting to a new normal. I use my time wisely and look at life with a new view. I'm working on projects that give me purpose and allow me to use my skills and expertise to change the status quo. I am using my nursing, case management, and patient advocacy experiences to help others who are thrust into the healthcare system, so they learn how to advocate for themselves or find an advocate to assist them when they need help.

Today, I write this blog, Nurse Advocate, to share information with patients, caregivers, and all members of the healthcare team to improve the healthcare delivery system. I thank God every night for giving me the strength to recover and help change the status quo in a small but meaningful way.

# The fear factor is never far away for patients

I wrote this post when thought I was going to have a recurrence of my brain tumor. I shared my feelings and what that experience was like, but I also wrote it as a message to oncology teams so they realize patients need help when they hear, “Your cancer is back.”

https://nursesadvocates.com/the-fear-factor-is-never-far-away-for-patients

As a brain tumor survivor, I know I have a high chance of recurrence. When I completed active treatment, I asked Dr. Lossos, my hematologist/oncologist, how long I would see him going forward. He said, “We are going to have a long relationship.” Well, that statement has proven to be true.

Six years have passed since I was diagnosed with a central nervous system lymphoma and was successfully treated with chemotherapy. As there is a high chance of recurrence, I have gotten MRIs frequently in hopes of catching anything early. I have been told the MRIs will continue for at least 5 years, as that is when a recurrence will happen if it’s going to.

In June 2015 I started getting an MRI with and without contrast every 3 months, followed by a checkup with the doctor. As scans were normal, the doctor stretched the scans to 4 months and then 6 months. I was beginning to feel somewhat normal, until September 26, 2017, when everything changed, and the fear factor kicked in in full force.

Here is the story: On September 19, I went for my 6-month MRI. A week later I went to the clinic for my follow-up appointment. As a patient with a chronic disease who sees the same physician many times, you get to know the patterns and routine of the clinic. I had gotten used to the routine with Dr. Lossos at our clinic visits, but this time a few things were different.

First, it seemed my wait time in the clinic was longer. I usually don't mind the wait, as I see the other people going in ahead of me and know how sick they are. So I read or stay busy with my phone.

But at this appointment, my husband, Corky, and I had an unusually long wait—two hours. As I finally entered the treatment area, I noted it was almost empty. We were put in a room to wait for the doctor. A few minutes later he came in. Usually he would come in, say hello, and sit down at the desk. He would get on the computer, look at my tests, and then turn to me and ask me how I was doing.

This time, he closed the door and stood there and looked at me. He said, "How are you—any problems?" He didn't take his eyes off me while he waited for me to answer. He looked at my husband and asked him: "How is she? Have you noticed anything different?" We both said, "No, nothing unusual," and we looked at each other a little worried. Corky asked how the MRI was. Dr. Lossos said we were going to talk about the MRI.

He went on to examine me as he usually did. Once done he sat down and looked at us and said there was a change in the MRI. He said he didn't think it was anything because a recurrence usually does not present the way the radiology reported. But he was concerned.

I had looked at the MRI report before the appointment, so I knew what he was worried about. I had been worried, too, but I thought maybe the radiologist over-read the scan since I felt ok. But being in front of the doctor and hearing him say he was worried raised my level of fear.

The radiologist who read the report had suggested a correlation with dedicated contrast-enhanced posterior fossa cross-sectional study and CSF analysis. Dr. Lossos said he didn't think those studies were needed at this point, as I was not having any symptoms.

The doctor said his plan was for me to have my next MRI moved up three months. If I had any changes or any problems, I was to call him right away; otherwise, he would see me again in December. We all agreed, and we left the clinic considerably more nervous than when we arrived.

I was scared, and I knew Corky was scared, too. We had been through hell during the first round. I was just getting back on my feet and we were finding our way to our new normal. We didn't want to go through cancer again, so we both prayed and hoped.

The time seemed to drag, but then suddenly it was time for the next MRI. I went to the cancer center where I'd had all my MRIs. Fortunately I'd had the same technician for many scans, so I told him what was going on. He said he would make sure the radiologist compared this scan with the past two, to be safe.

The MRI usually takes about an hour. I was used to the process since I'd had about 10 or so MRIs done over the preceding three years. Once in the scanner, the technician asked what music I wanted to listen to. I chose Christmas music! I was conscious of laying perfectly still so the technician could get a good picture, and I prayed we wouldn't find that my tumor had come back.

I left the appointment with the tech giving me a hug and wishing me a merry Christmas. He said he would say a prayer. Then I needed to wait one more week until my appointment with Dr. Lossos.

On the appointed day, we left early, as we were nervous to see the doctor. We made good time getting to Miami since traffic was light the day after Christmas. When we got to the clinic, the nurses were in good spirits and took me in right away to check my vital signs. They discovered they didn't have the correct blood work, so I needed to get blood drawn before the doctor saw me. We went to the lab and had the blood work done. We got back to the waiting room and were getting settled when we were called to see the doctor.

Dr. Lossos came in. He looked at me and said the MRI was fine. He knew we were worried and quickly reassured us with the good news. We were both so relieved and thanked him for letting us know.

The experience brought home to me again what it means to a patient. It is personal, scary, and lonely. I thought of the anxiety people go through when they have follow-up scans. A friend of mine calls it scanxiety!

Not knowing who to call or to ask a question is hard. As a nurse and a case manager, I usually check my patient portal before my appointment. This allows me to know what is going on and to prepare any questions I need to ask the doctor. During those three months while I waited for my MRI and clinic appointment, I read and reread the scan in question. I Googled the terms in the summary so I understood the terminology in the report. I understood that if what the radiologist saw was there, it would be serious. I knew I felt okay, and it was probably nothing, but the hint of doubt and fear was there. I wished I had someone to talk to who was familiar with the process, but I didn't want to bother the doctor and I didn't know who else to call at the clinic.

In the end, I was lucky. No recurrence…thank God. But what if I had not been lucky, and I heard, "Your cancer is back"—the words every cancer patient dreads. You got it once...you could get it again, right?

When I looked back on the experience, I tried to see how my experience of waiting for those three months could have been better. Granted, the doctor did reassure me, and I appreciated his words, but I would have valued talking to someone during the waiting period.

I also thought it would help for the doctor to flag my chart to let the oncology nurses know I might be having a recurrence. I would have been reassured if one of the oncology nurses who knew me were prompted to check in on me, to see how I was doing, and to remind me to call her if I needed anything. As with the initial diagnosis, being told you might have a recurrence is shocking. You don't hear the instructions or process the information as you normally do. A follow-up call from someone familiar would have been helpful.

Today there is much work going on in survivorship. I have not been part of a survivorship program, as my local program began after I completed treatment. But when a recurrence is being discussed, it would be a good time to introduce a survivorship program.

Many people who have abnormal scans and are waiting to learn their fate could use someone to talk to who understands the process and to help answer the questions that run through your mind. This support is needed and would be welcomed by many patients.

In closing, I hope this post raises awareness among those in charge of creating programs for cancer patients. I hope you realize that small things, like communication, empathy, and support, are what we want from our healthcare team, first and foremost. This is especially true during active treatment and when we’re waiting to hear about a recurrence or some other nerve-racking experience. These simple actions go a long way in relieving anxiety, helping people cope, and accepting the things we cannot change.

# The joys of travel as a disabled person

I wrote this post after my first trip as a newly disabled person to explain that travel is still possible and fun for those who are disabled. It was liberating to realize I could still travel and to share my story!

https://nursesadvocates.com/the-joys-of-traveling-as-a-disabled-person

I love to travel and considered myself a road warrior during most of my career. I found traveling fun, despite the challenges we all encounter as part of the process. Airports are getting bigger, and the distance between gates is longer. Flight schedules are also tighter, so getting from one gate to another can be a challenge, especially if your connecting flight was late.

As a newly disabled person, travel has changed for me. Now I need to prepare more, and I need to be cognizant of how I'll get to my gate when I arrive at the airport or how I'll get to baggage claim at my destination. If my flight is not direct, I need to make sure I request a wheelchair to take me to my next gate, as the distance between gates in most airports is quite long.

A few years ago, I was introduced to a reporter from the *Wall Street Journal* by a colleague. The reporter was doing a story on how airports are getting bigger, causing the walk to a gate to be up to a mile long. This is causing challenges for all travelers. The reporter wanted to discuss in his story how airport expansions have impacted the elderly and the disabled. I was glad to talk to him, as I had taken a few trips that opened my eyes to the challenges people experience when traveling—especially the elderly and the disabled. Here is the link to the *Wall Street Journal* article: www.wsj.com/articles/the-longest-walks-at-the-airport-1475082922

Travel is important to many people, whether able-bodied or disabled, and many readers of my Nurse Advocate blog are challenged by disabilities in one form or another. Other readers are healthcare professionals who can help their patients understand the challenges they'll face when they travel and how they can avoid problems by being prepared.

I have learned, as a newly disabled person, that I can still travel, but I need to take the time to prepare and to be alert for resources that allow me to navigate safely. Here are some of the tips that I have learned traveling as a newly disabled person.

The most important thing I can recommend is to plan ahead. Make a list of the things you'll need so you are safe and can continue your treatment during your journey.

Second most important is to make sure you give yourself plenty of time so you don't feel rushed and can handle setbacks. You'll decrease your anxiety and have a good experience.

Air travel for the elderly and the disabled can be a challenge but by preparing you can get the assistance you need. When you make your reservation online, you will see that most airline websites provide a box you can check if you'll require special assistance. If you do not see this box on the website, call the airline. Recently, I flew American Airlines and did not see a place to indicate I needed special assistance. When I called, the reservation representative told me they wanted people to call to arrange their special request. With the representative, I was able to arrange for a wheelchair between my flights.

If you won't be able to handle your luggage, check it when you arrive at the airport. This frees you up and reduces the possibility of forgetting or losing something. If you are carrying your bags onto the plane, make sure you are aware of carry-on rules and comply. On most airlines, you are allowed to carry on one small bag and an additional personal item, such as a handbag. If you attempt to carry on additional or oversize bags, you may have to check luggage at the last minute. For this reason, keep all medications in your personal item bag in case your checked bags get separated or delayed.

As I have to wear leg braces to ambulate safely, I usually ask TSA staff if I need to remove my braces to pass through security. Depending on the airline I'm flying and the security, they have allowed me to go through security without removing them. The alarm usually is triggered, and I then have to be inspected with the hand-held wand, but this extra procedure is not a problem because I arrive early and have plenty of time.

As a disabled person, most airlines allow you to board the plane early so you can store your luggage before general boarding. Many people with disabilities need extra time. By boarding early, you don't hold up the line while you get settled.

I have been impressed by the systems that various airports have in place for people who need wheelchair assistance. Most times, my wheelchair is waiting for me when I deplane. The people pushing the wheelchairs are courteous, help you with your bags, and make sure you get into the wheelchair safely. I have been asked if I need to use the ladies room before getting to my gate. I thought this was so thoughtful. If the distance between gates is long, you might be transferred to an electric cart. Again, most of the major airports have their systems down to a science and are efficient in getting passengers from one gate to another. It is customary to tip the wheelchair attendant for this service. If you are satisfied with the service, please be generous, as these people work really hard.

For those with ambulatory issues, once seated we are usually okay. If you have other needs, however, such as oxygen, the flight attendants are very helpful in getting you set up. Again, making arrangements ahead of time helps prepare the staff. Fellow passengers are also usually helpful to those with special needs, so don't be afraid to ask for help if you need it.

If you are traveling by another means, like a train or bus, there are similar resources available when requested.

When we went on a cruise, the ship provided resources for those who needed assistance with a variety of needs. Don’t be afraid to ask for help, as it usually can be provided, or accommodations can be discussed.

I shared our cruise experience and how it compared to the customer service in the hospital in a post on Nurse Advocate titled Going Beyond Expectations to Create a Culture of Caring (https://nursesadvocates.com/going-beyond-expectations-to-create-a-culture-of-caring). The article provides good suggestions for proficient customer service, which may be of interest to those working in healthcare.

If you are going to stay in a hotel on your trip, consider asking for a handicap room when you make your reservation. I have been disappointed in some hotels, as their handicap rooms were not always well-equipped for my needs. So be careful when you’re in a hotel, as it is different from your home. Things you take for granted at home might not be the same in a hotel. For example, the towel rack may not be sturdy enough to hold your weight if you find yourself off-balance and needing something to hold on to. When you arrive, scan the room and bathroom for sturdy things to hold. Check the shower grab bars to be sure they are sturdy.

Make sure you pack your medication, as well as any equipment you need, and keep it in your carry-on bag. On a recent trip, I forgot my medication. I called the local Walgreens. (I also use Walgreens at home.) Unfortunately, the cost for a few pills was prohibitive, as I was between refills. Thankfully my husband was home and could overnight a few pills to where I was staying so I stayed on schedule.

If you need other equipment while you are traveling, talk to your doctor. If you are working with a case manager or a patient advocate, ask them for advice and assistance, as they will be able to help you make arrangements for equipment to be delivered to you once you arrive at your destination.

As with everything I do now, planning is important. By taking the time to prepare, I realize I can still travel and enjoy life.

# What to do while waiting

I wrote this post to share one of the most difficult things people who are patients or caregivers do—WAIT. It was eye opening to me how long people must wait in our healthcare system, and how common acts of courtesy can make the waiting bearable.

https://nursesadvocates.com/what-to-do-while-waiting

We all experience waiting on a daily basis. We wait in supermarkets, at traffic lights, and in so many other aspects of our daily lives. So why was waiting one of the most difficult challenges I endured as a patient? I wanted to share my thoughts and the ideas I came up with that helped me pass what seemed like unending waits times.

For me, one of the most difficult aspects of being a patient was losing control of my time. So many times I was on someone else's schedule, and I had to wait for others to help me do simple things that I could no longer do for myself.

During chemotherapy treatments, I had to stay in the hospital extra days, as my body did not clear the chemo in a timely manner. I slept a lot during those stays and again when I came home due to the effects of the chemo on my body. In retrospect, I lost a lot of time I'll never get back. Since then, I cherish every day and try to make the most of my time.

In the hospital, I would get frustrated when I had to wait for an aide, a doctor, or a nurse, as I didn't know when they were coming back. Minutes seemed like hours, and I occasionally felt like they didn't value my time, which was upsetting. I knew the staff was busy and I was not their only patient, but that rationale only lasted so long.

What helped me better understand the reason for a delay was when someone took the time to explain why I was waiting. This simple acts of courtesy made such a difference and allowed me to better understand the situation.

It was also reassuring to know that staff recognized waiting was uncomfortable and at times distressing. It was so appreciated when a nurse or secretary would recognize that I was still waiting and would smile at me, letting me know they hadn't forgotten me. Many took the time to let me know I was next or to ask me if I wanted a blanket, something to drink, or a more comfortable chair. These simple acts of kindness let me know I mattered and was not forgotten.

Many of my visits were to hospitals, clinics, laboratories, radiology departments, or doctor's offices where the temperature felt sub-zero. My husband and I both learned to dress for warmth. Occasionally there were blanket warmers, which was a nice treat….but bringing a sweater and wearing socks to keep my feet warm really helped when the office or clinic didn't have a blanket to lend.

I always knew I would likely have to wait, so I passed the time doing things that were important to me. Here are some ideas:

I always made sure my smart phone was fully charged. If I knew I'd be gone all day, I would also take my charger. I tried not to talk on my phone unless I was in a private room or a secluded area so I did not disturb others, but I did text and email to communicate with family and friends while waiting.

I also logged onto social media sites like Facebook, LinkedIn, and Twitter. I could read what everyone was doing, catch up on news, and stay connected with people who were going about their daily lives.

It was important to me to keep up on trends in healthcare. I shared posts I thought colleagues would appreciate. Reading people's responses allowed me to know I wasn't alone and I still had friends and colleagues who valued my opinions and suggestions. I was glad that most of my visits took place in buildings with free Wi-Fi, which allowed me to stay connected.

Talking to staff, such as the housekeepers who cleaned my room, the aides who made my bed, the nurses who gave me my medications, or the workers who delivered food trays, also helped pass the time. Most were glad to talk and joke with me as they did their work, and they appreciated being recognized for what they were doing. I made good connections and many of them would stop in to say hello and ask me if I needed anything. This always made me feel good and let me feel that I was part of the team.

During many of my wait times, I would make lists of things I needed my husband to bring. Sometimes it was a book I wanted to read or clean clothes to wear if my stay was extended.

I also wrote my "bucket list" of places I wanted to go, people I wanted to see or call, and things that I wanted to do when I got home. This helped keep me focused and feel useful.

Another pastime I discovered was coloring. Adult coloring books were a new craze that many people used to relieve stress.

Many times I simply said my prayers, which helped me relax and let go of some of the fear and frustration that I felt.

Waiting gives us the time to slow down, to reflect, and to organize our lives.

Please share this post if you know someone who is in the hospital, has a lot of doctor's appointments, or is getting treatment that causes them to spend a lot of time alone and WAITING.

## Chapter 2

# Tips To Make Your Journey Successful

# 10 tips: To prepare, reduce risk, and be smart

This post shared how a life-changing experience changed my perspective on being prepared.

https://nursesadvocates.com/2250-2

Few of us take the time to prepare for a life-changing event. We live our lives, take care of ourselves as best we can, and don't think about challenges that may occur.

If you have ever experienced a life-changing event, you shift your thinking and begin to look at life with caution. You think about ways to prepare because we know we are human and things happen when we least expect them.

I had this experience in 2014 when I was diagnosed with my brain tumor. My life changed in seconds. I have learned the importance of being prepared.

I want to give some tips I hope you'll take to heart and share with your family, friends, and colleagues.

1. Make sure you have health insurance: If your employer offers health insurance as a benefit, sign up for it. Employee-sponsored health insurance is the most reasonable way to purchase healthcare insurance. If your employer does not offer you healthcare insurance, check out the Healthcare Marketplace for a policy. The Healthcare Market Place was formed in 2010 as part of the Affordable Care Act. An individual policy is expensive, so shop around for what's available in your state.

2. Get your expenses under control. If you have high credit card debt, try to consolidate your bills so you can get them under control. There are organizations to help you do this, so do some research.

3. Know your income and expenses. Make a budget so you can know your expenses, and have a plan to save on a regular basis. The earlier you do this, the better, but it's never too late to start. My father was always making me a budget so I could pay my bills and learn how to save. I never really appreciated that, but his work has paid off in more ways than I ever imagined. There is a saying: “Pay yourself first.” Put money away, even a small amount, for a rainy day. Savings are critical for everyone, whether it be to plan a vacation, buy a house or a car, or pay unexpected medical bills.

4. Think about setting up a medical savings account. Having one will help you pay your deductibles and out-of-pocket costs. Today many people have high deductible health insurance plans with high out-of-pocket costs that must be paid before the health insurance policy provides coverage. If you have a terrible accident or are diagnosed with a medical condition, you will have to pay your deductible and any out of pocket costs BEFORE you receive care. Having a savings account for these expenses will allow you to get the care you need.

5. See if your employer offers disability insurance. Many employers provide this type of a policy at a reasonable rate. If so, sign up. Disability insurance will help you have an income if you're not able to work due to an injury or

significant medical condition. Policies are activated in various ways, so make sure you understand what you are signing up for. Disability insurance will help ease financial hardship if you are injured or hit with a severe medical condition.

6. Get your Advance Directives in order. Advance directives allow your loved ones to know your wishes in case you cannot express them yourself. Have your advance directives drawn up now and update them from time to time as you age.
7. Take the lead with your family and have a conversation as to what each of you wants to happen if you cannot speak for yourself. Ask someone you trust to be your health surrogate and another trusted friend to be your financial surrogate. Different people should fill these roles. Get your paperwork in order and let your family know where your relevant documents are. Don't wait for a crisis to occur. Share the information with your family so in case of a catastrophic event, decisions can meet your wishes. Hopefully, it will spur other members of your family to take the same action.
8. Get your spiritual life up to date. Make peace with those you may be fighting or have unresolved conflicts with. Tell your family and friends how much they mean to you.
9. If you have children, make sure they have healthcare coverage and are up to date on their vaccinations and other medical preventative tools as part of their wellness plan.
10. Get your annual check-ups and take care of yourself. You are worth it!

I hope these 10 points help you, your family, and your friends to be prepared for the unexpected.

# Lesson learned: Knowing the difference between a referral and an authorization

This post shares an experience that could have cost us a lot of money and precious time.

https://nursesadvocates.com/lesson-learned-knowing-the-difference-between-a-referral-and-an-authorization

I learned that, in the HMO world, referrals and authorizations are intertwined. On one occasion, my husband was seeing his primary doctor in follow up for treatment for a Deep Vein Thrombosis (DVT). During the previous visit, the primary care doctor had mentioned my husband might need to see a cardiovascular surgeon. In anticipation for this appointment, we looked on the HMO provider website to see which cardiovascular surgeons were in-network so we could give the doctor the list of providers. Several cardiovascular surgeons were in-network, so I printed off the names and put the paperwork with my things to take to the appointment.

During the visit, the primary care doctor did say he wanted my husband to see the cardiovascular surgeon. I handed him the list I had printed off. He reviewed the list and said he knew a few of the doctors and recommended one on the list. He went out and came back a few minutes later and handed us a form with the referral noted. He said he'd see my husband again in a few weeks and said goodbye.

We left the office and went home. I called for the appointment for the cardiovascular surgeon and gave the insurance information to the staff person making the appointment. We lucked out and got an appointment for the following week!

On the appointed day, we went to the clinic for our 8:00 am appointment. When we approached the registration desk, the receptionists started the intake and then asked for the authorization. My husband handed her the paperwork we had gotten from the doctor. The receptionist looked and it and said this is a referral, not an authorization. She showed me what an authorization looked like and said, "This is what I need to register him." My husband asked, "How do we get the authorization?" She replied that you get it from your primary.

It was 7:50 am, so I knew the doctor's office wouldn't be open. The receptionist suggested we reschedule. My husband didn't want to do that, so we asked what the out-of-pocket cost of the appointment would be. She told us it would be $200, and whatever the level of care was. She said the doctor would tell us the level of care after he saw us. She also said that if any tests were ordered, we would have to pay more. My husband gave her his credit card. The receptionist scanned it in to the system and finished the check-in.

We were called back shortly and saw the doctor. The doctor examined him and reviewed his findings of the Doppler study he'd had the previous week. He gave us the plan of care, which we agreed with, and we left.

The nurse told us to see the receptionist again on the way out. She added the level of care to the cost of the visit and told us we owed another $85. I asked if she could wait to run the credit card while we tried to get the authorization. She said she had already run it, but if we got the authorization and had it faxed over before 5 pm, she would cancel the credit card charge. We thanked her and left.

After leaving the office, we went right over to the primary care doctor. We explained what had happened, and the receptionists said, “Let me run the authorization right now.” She came back a few minutes later with the authorization. We also had a minute to talk to the primary doctor and reviewed what the cardiovascular specialist had recommended. He agreed with the plan and said he would see us in a few weeks and to call him if there were any issues.

My husband then went back to Cleveland Clinic and gave the receptionist the authorization. She said she would cancel the charge.

Lessons learned:

- If you have an HMO, know that to see a specialist, get specific tests, or have therapy, you need a referral *and* an authorization from your doctor.
- Know that a referral is different from an authorization. The primary care office knows how to get the authorization from the insurance company. It is usually done online and takes a few minutes, so don’t leave your doctor’s office until you know they’ll run an authorization. You might be able to wait for it, but if you don’t wait, get a name and the phone number to check on the authorization if it doesn’t come through in a timely manner. You will need the authorization or you won’t be seen—or, as noted above, you’ll have to pay for the visit out of pocket.
- Check to see if the primary care office will make your appointment so they can check that the specialist has the tests or services you need. Often they will do this for you.
- If you have a specific request as to which specialist you want to see, make sure they’re in your HMO network. Staying in your network is critical, as going out of the network is more expensive for you.
- If something like our experience occurs, don’t give up. See what the receptionist will do for you.
- Don’t be afraid to pay for a service if it’s important to you. It can save you time, and it will allow you to “do what you need to do” without delay. Most times, you will be reimbursed by your insurance company.

- Remember, you are the customer, and you have a voice. As they say, “Everything is negotiable,” so don’t be afraid to speak up and ask what can be done to remedy a situation.
- Read your insurance handbook. It contains important information regarding your policy that will help you be better informed.
- Know there are rules to follow when it comes to insurance. HMOs are the strictest of all the insurance policies.
- Take time to learn the various types of insurance. Check with your employer to see what options you have for an employer-sponsored plan. Some employers offer a PPO option in addition to the HMO option. A PPO gives you a little more freedom, but it’s more expensive. If you’re buying insurance on your own, study the various policies and choose the one that is right for you.

Since having this experience, we’re aware of the rules and what we need to do if our primary physician orders a service or suggests we see a specialist. We now know there’s a difference between a referral and an authorization!

# Don’t assume

To ensure a good experience, the patient and family must be prepared.

https://nursesadvocates.com/dont-assume

My husband went to see his primary care doctor for follow-up on tests he’d had done two weeks earlier. When the doctor walked in the room, he asked, “Why are you here?” My husband replied, “I’m here to follow up on the lab and ultrasound you ordered. I came today to get the results, as I thought you would want to review them with me.” “Oh right...” said the doctor. “Let me see if we have the results.”

He looked through the computer and said they weren’t in the chart. The doctor said he’d ask the staff to gather the results, but it could take a while, so he’d call us once he had them to review. My husband asked the doctor a few more questions, and we left.

As we drove home, he said he was frustrated. He was anxious to know the results of the tests and felt that the appointment had been a waste of time.

We both learned a good lesson: We could not assume the staff would make sure the results of my husband's tests would be in the system. It's essential for us to do our homework before we go to a doctor's appointment.

I have to make a confession here…I was the one who made the appointment. I should have asked if the results were back from the various providers. The staff could have checked, and if they weren't back, they could have called for them.

As a nurse advocate, I would never go to a follow-up appointment with a patient without having checked that any diagnostic tests or consults had been sent to the doctor in time for the appointment. Why didn't I use the same process for my husband's visit? Why did I assume this office would be more efficient than any other doctor's office I visit with my clients? As they say: Don't assume!

Today, as the burden of risk moves more and more to the patient, we are expected to take more responsibility in our health and healthcare.

If we want our appointments to be efficient, it's up to us to see if the test results were sent to the doctor to review. Don't leave it up to the office staff; do it yourself. Take responsibility for your care.

Another way to prepare for your doctor's appointment is to review your patient portal. Today, doctors and hospitals are required to provide patients access to diagnostic test results, progress notes, consultation reports, and other information doctors use to coordinate care.

Checking your patient portal keeps you up to date and helps you coordinate your care. If you're not using your patient portal or aren't sure if your doctors' office has a portal, ask the office staff about it. Usually, the front office staff will send you a link to join the portal. Once in, you can view past office visit notes and any tests you had. You can even look up your bills to make sure you have no outstanding invoices. In addition, you can communicate with your doctors and make appointments through the patient portal.

You can also print off tests and share the information with other physicians you see. Unfortunately, there is still no coordinated system that links all providers together, so if you see five doctors in separate organizations, you might have five portals. Progress is being made on a coordinated system to share information efficiently, but in the meantime, don't let this hold you back.

As a nurse advocate, I ask clients to give me permission to access their patient portals. I do this on my clients' HIPAA consent form. Access to clients' portals makes my work more efficient.

Being prepared is integral to all aspects of our lives. We need to take the same approach with our medical care! Remember, YOU are the only constant in YOUR care, so YOU need to take the lead to make sure your care is coordinated.

# How many portals do you have?

Learning how to use your patient portal can be a time-saver for everyone.

https://nursesadvocates.com/how-many-patients-portals-do-you-have

Today, patients are encouraged to use patient portals to keep up to date with lab work, appointments, payments, and doctor visits. In theory, this is a great idea, but complex patients often have multiple patient portals, making the system fragmented, disconnected, and time-consuming.

To illustrate the point, I am sharing an article written by Morgan Gleason, a 21-year college student with a chronic medical condition. It was published in my organization's publication, *CMSA Today*. The article was titled, "Why Patients Need Full Access to THEIR Medical Record."

In it, Morgan shared her experience of being a patient with a complex medical condition. She wrote, "My medical records are stored in silos at different doctors' offices, hospitals, labs, and surgery centers. I have 23 different patient portals that all have different versions of my information, which are often outdated or incomplete. Only one of them lets me see the office visits from my doctor's appointments. Not only do I not have access to my information, but my doctors are often missing critical information they need to treat me. The burden falls on me, the patient, to keep up with all of this information and to share it with them. It makes me wonder why this is happening, when in reality, I am the only member of my team, out of all my doctors and nurses, who is not being paid to help keep track of everything! You can imagine that, as a 21-year-old, I would much prefer having an app on my phone that updated as my doctor's electronic records system was updated after my visit. Having access to my information would allow me to know what was going on and share the information with other providers who might not be on the same system."

A Federal Rule has been announced to do just what Morgan suggested. As a result of the 21st Century Cures Act, patients are more in charge of their health records. This allows them to be better informed when they make decisions regarding their care. Additionally, having access to information allows them to coordinate their care with their healthcare team.

It is recognized today that people need more power/control/say in their health care, and access to information is key to making that happen. Open Notes, a research organization, has studied that when patients have access to their medical records, they are more informed and make better healthcare choices, which improves the quality of care they receive and controls healthcare costs.

Today, when we can make airline reservations on our phones, why can't we access our healthcare information the same way? The technology is in place, but the systems appear unwilling to give up their control.

Unfortunately, while we are not there yet, we are getting closer. All patients need to use their voices, as Morgan did, to make sure the government mandate is implemented across the care continuum.

In the meantime, here are some steps you can take to be an empowered patient.

1. Set up your patient portal with the doctors you see the most.
2. Check your portal often so you become familiar with how it works.

3. If you have questions, there are people to help you navigate your portal. Ask your doctor's office who to call if you have questions.

4. Only share access to your patient portal with people you trust.

5. If you need help interpreting the information in your portal, your doctor should help you. If your doctor can't or won't help you, find a case manager or a patient/health advocate to help you. That is what they do: help you understand your care and medical information.

6. Stay informed as changes occur in healthcare.

7. Use your voice if your doctor or hospital does not use a patient portal. Send a letter as to what you would like to see to your doctor, your insurance company, and your members of the House of Representatives and the U.S. Senate.

Explore these topics to learn more:

- Morgan Gleason's article: Why Patients Need Full Access to their Medical Records in Issue 3 of *CMSA Today*. https://www.cmsatoday-digital.com/cmsq/1120_issue_3__2020/MobilePagedArticle.action?articleId=1573352#articleId1573352

- Open Notes is an essential resource for patients/caregivers and all healthcare professionals to stay updated on information sharing. https://www.opennotes.org/onc-federal-rule

- The 21st Century Cures Act. https://www.healthit.gov/curesrule/what-it-means-for-me/patients

## Chapter 3

# Be an Active Member of Your Healthcare Team

# Nine tips to get patients actively involved in improving their health outcomes

This post gives readers 9 tips for becoming active in their health and health care.

[https://nursesadvocates.com/9-tips-get-patients-actively-involved-improving-health-outcomes](https://nursesadvocates.com/9-tips-get-patients-actively-involved-improving-health-outcomes)

You can't pick up a paper or listen to a news show without hearing a piece on the challenges taking place in our healthcare system today. This attention is warranted, as according to Centers for Medicare and Medicaid Services, healthcare spending in the U.S. is at $3.3 trillion, or $10,348 per person. As a share of the nation's gross domestic product, health spending accounted for 17.9 percent. We're told that we as a country cannot sustain this spending because it impacts what we have left to spend on other important areas, such as education, infrastructure, and addressing the needs of the population as a whole. In addition to escalating costs, people who use the healthcare system are not satisfied with the care they receive.

## The move to value-based care

As a result of the rising costs of healthcare and poor satisfaction ratings, hospitals, physician practices, and all stakeholders are working hard to come up with innovative ways to contain healthcare spending and improve the patient experience. The U.S. government has worked on this issue over the years and has come up with various programs to try to curb spending. The latest strategy involves value-based programs that reward healthcare providers with incentive payments for the quality of care they provide to people. These programs are part of a larger quality strategy to reform how healthcare is delivered and paid for. Value-based programs support three goals:

1. Better care for individuals
2. Better health for populations
3. Lower cost

Currently, this strategy is working its way through every sector of the healthcare system, with mixed results. What healthcare professionals are finding when they analyze the roadblocks, is that the patient is the missing link to making the project work.

Healthcare professionals are learning that value-based care does not work if patients and their families, as the consumers of healthcare services, are not involved in the process.

Healthcare leaders and professionals are starting to realize that the patient has to be part of the team, since they're the only consistent member of the team. All other members may change over time, but the patient and their family caregivers remain the same.

They are also realizing that patients' goals and the goals of the healthcare system do not always align. All members of the healthcare team need to understand the goals of each patient they care for so the plan of care can be designed to meet the *patient's* goals.

## How to get patients to join YOUR value-based care team

Here are nine tips to share with your patients to help them be the captain of their healthcare journey. Help patients put these tips into their routine to improve their care and health outcomes:

### 1. Find a healthcare advocate

As a nurse for over 40 years, I thought I knew how the system worked. But becoming a patient, one who was impaired cognitively for the first few weeks of my healthcare encounter, taught me that regardless of my experience, I needed an advocate. Having someone with you is critical to ensure you are safe and have a voice in your care.

A patient advocate can be a family member or a friend who has time to accompany the patient to medical appointments and to visit them in the hospital. As family members and friends are often busy people, patients may need more than one person to act as their advocate. Patients should take time to look at their circle of family and friends to see who can help them. They should also choose people who will help them carry out instructions from their medical professionals to improve their outcomes.

Patients should also talk to their advocate(s) ahead of time about their wishes and share their advance directives. Communication is key between the patient and their advocate. Five Wishes is a great tool to get patients thinking about advance directives.

### 2. Get patients involved in advocacy groups

One way to help patients stay involved in their healthcare organization is encouraging them to join their Patient and Family Advisory Council. Doing so allows the organization to understand the needs of the patients and caregivers who utilize their services. Today, quality, safety, and the patient experience are tied to reimbursement, which adds to the revenue of hospitals and doctors offices when outcomes are positive. Organizations that understand their patients and the caregiver's perspective are able to make improvements. Most hospitals have a Patient and Family Advisory Council that welcomes volunteers.

### 3. Complete patient surveys

Encourage patients to complete the short surveys they get after a visit. People are paying close attention to these surveys, so they're well worth the small amount of time it takes to complete them. Encourage your patients to be honest with their input and offer a suggestion for improvement if they have a complaint. Remind them, with their input, improvements can be made.

### 4. Review their face sheet

Most patients don't know what a "face sheet" is. The face sheet is the document healthcare providers and staff refer to for information about patients—including contact info, medical history, patient's preferences and wishes, etc. Often the information on the face sheet is wrong. Patients should have a chance to review their face sheet when they're scheduled for an appointment or admitted to the hospital. Having patients review the information will help ensure they get the highest quality of care possible.

### 5. Communication is key

Patients, especially ones who are receiving chemotherapy or other types of treatment that leave them open to serious infections, should always feel comfortable calling their doctor. If they get a fever, notice a rash, or feel sick, they should know it's okay to pick up the phone, even if it's after hours or on a weekend. If the physician is not available, there will be an on-call doctor who will return the patient's phone call and give appropriate direction. If no one returns their call, be sure your patients know they should go to the urgent care center or emergency department. They need to be sure it's not an infection that will become serious if not recognized early.

### 6. Prepare for the visit

Whether it's a doctor's visit, a therapy session, or a hospital stay, patients should always prepare to make the most of their time with providers. Encourage them to write down questions or concerns they have. No question is stupid or unnecessary. Healthcare providers cannot anticipate every problem, so having patients share their concerns or questions is the best way to meet the patients' individual needs.

### 7. Utilize patient portals

Patient portals provide a way for patients to communicate with their doctors and access their medical records. Information on the organization’s patient portal system and how to access it can usually be acquired at the front desk. Some patient portals can make checking on lab or other diagnostic tests easier. In addition, insurance companies also have a portal where patients can review bills and ask questions related to insurance. These are important tools that can help the patient stay actively involved in their care.

### 8. Keep records

Patients should be advised to get a binder and put copies of their medical records into the binder. Having those records in the binder will allow them to pull out a document a provider may not have seen. Keeping the provider informed allows the patient to avoid duplication of services and medical errors.

### 9. Share their stories

It’s also important for patients to share their stories. If they have an idea on how to better advocate for themselves, they should share so others can learn too. Patients can participate in social media groups, contribute to blogs, or join support groups for their similar care population.

I hope these tips help patients receive the best care possible. Remember, patients are the most important member of the healthcare team. Keeping them involved will help improve their care and outcomes.

# Setting expectations in a complex healthcare system

This post explains an important role I play in helping people understand the complex healthcare system.

https://nursesadvocates.com/setting-expectations-in-a-complex-healthcare-system

I have written a number of posts on the experiences I've had with clients I'm working with as a nurse advocate. Each person came with unique issues related to their health. One patient had a suspected deep vein thrombosis, one was diagnosed with a recurrence of lung cancer, and the third person had a GI bleed with multiple co-morbidities that took months to identify and get under control.

My role was always to support them by helping them navigate the complex healthcare system by breaking through the barriers each client faced. These barriers included getting appointments in a reasonable time frame, researching specialists who had the expertise to diagnose and treat them (and who were in their managed care network), working through the complexities of authorizations, payment, and reimbursement issues that accompanied each visit.

Most members of the healthcare system know these issues are commonplace and “just how it is.” As a result, one of the most challenging parts of my job as a nurse advocate is setting my clients’ expectations.

I do this by explaining the situation and letting my client know I care. I go to the best person to address the problems and then explain the reasoning to the client. Most of the time, this pacifies clients but doesn’t relieve the stress they feel.

I work to communicate professionally with various healthcare providers. This isn’t always easy, as most are not used to patients being accompanied by an advocate who asks questions the average person does not. Many healthcare providers do understood my role is to support the patient and help the provider as they work with the patient to design a plan of care for their condition. Communication has been a constant struggle that is frustrating to me and distressing to my client.

In a system that is overloaded, stressed, and very complicated, setting expectations is not an easy job. Three things I have learned include:

- The importance of building a good relationship with both my client and the various members of their healthcare team. I tried to show each that I cared and that I would work with them as best I could to address the challenges each faced.
- Employing two-way communication. I ask the client what they want, and then try to communicate this to the staff and their physicians. I listened to the staff voice their challenges and how we could work around those issues.
- Being proactive when things go wrong. I addressed problems and tried to offer solutions calmly and professionally.
- Remembering my clients want to be treated with respect and have their healthcare providers address their needs so they could return to their lives.

It isn’t easy, but writing about this topic has helped me reflect on what I do with fresh eyes. I learn something new with each encounter, and that has allowed me to see how I can handle situations in a way that meets the client’s expectations.

# You gotta have goals

I had to adjust to my new normal as I recovered from my brain tumor. This post resonated with readers, which made me feel good, since staying positive and setting goals gives us purpose when we need it most!

https://nursesadvocates.com/you-gotta-have-goals

Most of us have been told since we were young that it's important to set goals. Goals provide the direction we need on the journey we call life. Our goals may change as we age or be redirected in the face of challenges, but keeping goals in mind can help you to get back on track when dealing with life's speed bumps.

Many people, when faced with a life-changing event, feel that they miss the opportunity to set goals. There are good reasons for this feeling this way. Fear, anxiety, pain, and a number of other challenges can impact your ability to think about next steps. Yet many times a diagnosis or health emergency can motivate us to set goals, get our lives in order, and take the time to enjoy life.

When I was in the hospital, I was worried about how my life would proceed with my brain cancer diagnosis and the effect the treatments had on my mobility.

I voiced these fears to my doctor, and he felt it might help if I met with a psychiatrist. I was leery at first, as I didn't want to be labeled as depressed, but I agreed to see the psychiatrist. The doctor my team called in was able to see me while I was an inpatient. My husband and I were able to sit down with the psychiatrist in my room and discuss my diagnosis and other issues that were on my mind. She asked me how I felt about losing my job due to my condition. We talked about the fears I had about recurrence and the fact that currently I could not walk or drive. Having an opportunity to vocalize my feelings allowed me to process all the information better.

In addition to my fears, I was also able to share some things I hoped to do as I recovered. I let her know I was excited about a trip we'd planned to celebrate my husband's 60th birthday and how I hoped I could still make the trip. She asked me questions that helped her determine how I was handling things.

When we were wrapping up the meeting, she said she didn't think I needed medication. It was her opinion that I was handling the current situation well. She said she was impressed that I had goals and was looking forward to the future, despite this untimely interruption. She said the things I was feeling were normal, and I needed to give myself time to work through the changes and my fears.

Today, I still have many of the fears that I expressed to the doctor that day. But as I get more control over my condition, and as time moves on, I feel more positive and have begun to put many of my goals into action. The Nurse Advocate blog that brought about this special report was one of those goals!

Here are some things I learned about the importance of having goals:

Having goals is important for many reasons. They allow us to think about things we want to do instead of the challenges that are limiting our abilities. Goals help us put our priorities in order and live more in-the-moment. Don't feel like you must meet every goal all at once, though. List them, then put them in order of priority for yourself and your family. Talk to those close to you about your goals. Sharing your thoughts allows others to help and to better understand your wishes.

To help you better understand what I mean, I have listed some goals you might want to consider if you're living with a new diagnosis or a chronic condition, have suffered a life-changing illness or injury, or even if you're healthy.

1. Learn all you can about your condition. Give yourself time to do this; ask your doctors and/or members of your medical team for information that will help you understand your condition. Many people go to the internet for information, but without much direction. There is a lot of information on the internet that might not be accurate or relate to you, so asking your doctor or team for sites they recommend will help you find reliable, pertinent information.

2. Take charge: Do more for yourself if you can. For example, take your medication yourself or follow up on your appointments. You might want to organize your bills so you can review them to ensure your insurance company is paying and if you owe anything you will know if the services were provided. Bills can have errors, so check them carefully. If you have questions, you can then call the provider or the insurance company. Try to be as self-sufficient as you can.

3. Don't be afraid to ask for help. Many people want to help you, and it's important to let them. Make a list of things that you might need from the store. When someone asks what they can do, show them the list. Help from family and friends can allow you to get outdoors occasionally, as well as give your caregivers some needed time off.

4. Find out what you can do to improve your condition. This might be exercising to build up your strength after being in bed for a prolonged period, or learning how to test your sugars if you're a newly-diagnosed diabetic. Many people must monitor their blood pressure to see if their medication needs to be increased or decreased. Depending on what needs to be done, ask your team for the equipment and instructions on how to perform the task. Today, patient education is very important and should be part of the plan of care, so don't feel you're bothering someone when you ask for help.

5. Read a book, color, paint, or finish a project you started a while ago. Doing these things can take your mind off yourself, lift your spirits, and provide a sense of accomplishment.
6. See an attorney and get your affairs in order. Many people don't have a Last Will and Testament. Having an illness or an injury can be the impetus to spur you into action. This will help you and your family if you aren't able to express your wishes. Not having a will puts your estate (even if it's a small estate) at risk. Taking care of this early on is very important and will give you peace of mind.
7. Set up a healthcare proxy and inform the person you choose what you want to happen in case you cannot make decisions yourself. Having your proxy and your family understand your wishes allows them to speak to the medical team and ensure that the plan of care is meeting your goals. This will also be part of what the attorney will assist you with when you set up your will. When choosing a healthcare proxy, choose someone you trust, and share your wishes with them and your family so all are aware. Knowing you have this taken care of will give you peace of mind.
8. Make amends with people you've had challenges with in the past. You can do this by sending a note, an email, or calling on the phone. This may seem hard, but in the end, you will feel better and be more at peace.
9. If you are spiritual and/or religious, renew your faith. Having something to believe in can help you cope with the challenges of an illness or injury. It is never too late. Many religious organizations have programs where people come to your home if you cannot go out.
10. Keep in touch with family and friends; renew your friendships and your relationships. Invite people to visit you so they see you when you are alive. This can be uplifting for you and the other person. Call people and stay in touch. Today, with email and social media sites like Facebook and LinkedIn, this is easier than ever.
11. If you have a family event coming up, prepare to attend if you are able. Whether it's a wedding, a birth, a birthday party, or another event, going will

mean a lot to your family and friends. It will also give you something to look forward to and allow you to feel more connected. Make sure you have the equipment you need to be safe when you travel and make the necessary arrangements. Your doctor's office will assist you with the necessary equipment, along with providing any notes you might need to travel. Plan ahead so when the event comes you're ready.

12. If you can take a vacation to someplace you've always wanted to visit, do it. Don't put things off. Remember, life is short and very unpredictable.
13. Celebrate your successes! Even the smallest ones are important!

Having goals can give you control at a time when you feel like life is spinning out of control. Setting goals helps you focus on what's important to you. Make a list and keep it close to you so you can add to it or check things off as you go.

# The patient is the only constant when it comes to their health and healthcare. Let's listen to them.

This post shares an experience I had with a 97-year-old women who I empowered to speak up to her doctor when she knew something wasn't right.

https://nursesadvocates.com/the-patient-is-the-only-constant-in-their-health-and-healthcare-listen-to-them/

In a doctor's appointment with a client, I learned my client's liver enzymes were elevated. Her chief complaint had been extreme fatigue, so the hematologist had ordered tests. When the labs were back, he looked over her medications and found that one of the drugs could cause elevated liver enzymes.

During the visit, the doctor explained to the patient and me how elevated liver enzymes could cause extreme fatigue. He recommended that she come off one of her meds thought to cause the problem. I asked the hematologist if he would call the cardiologist and explain what he was seeing and discuss some of the options.

The doctor said, "No, the patient has to do this." He said we're all specialists, and we don't tell each other how to practice.

This encounter made me think: Have we really made any progress in improving communication? Is the theory of care coordination only in textbooks?

I recommended to the patient that we see her cardiologist, bring the lab work, and have other tests performed to evaluate her complaint of fatigue. The patient agreed, so I made the appointment and asked the patient to talk to her two sons to ensure all were in agreement. The patient and her two sons had a call to discuss the situation. On the call, the patient explained that being so tired was impacting her quality of life. She understood she was on the medication due to her heart condition. But she was willing to take the risk and stop the drug if it was responsible for causing her fatigue. The sons agreed and asked me to explain this to the doctor.

On the date of the appointment, I accompanied the patient to the cardiologist's office. The doctor came in and asked the patient how she was doing. She explained to the doctor that she was extremely tired despite sleeping well. She was also having tremors that were impacting her ability to do simple things. He reviewed her lab work and her mediation. He said she needed to be on all of these meds to prevent a heart attack.

The patient explained that she could not stand living like this. She said her son told her that a few of her medications could be causing/adding to the fatigue. She asked if she could come off the medication in question to see if it helped. The doctor re-evaluated the reports and said ok, let's stop a few of your medications to see if it helps. He said he'd see her in two weeks and to go to the ED if she had any chest pain.

I was proud of the patient as she talked to the doctor. She advocated for herself and helped the doctor see that even though the protocol called for a specific plan of care, the patient side effects warranted a re-examination of the plan of care.

The patient is medically complex. Having four different doctors manage her care is challenging. As the nurse advocate, my job is to listen, use critical thinking, and work to keep each doctor informed by bringing to their attention problems that arise so they can make decisions. My role is also to empower the patient to speak up when something is not right. I feel like I did this as best I could. To end this story, the patient did come off the drug in question and is doing well.

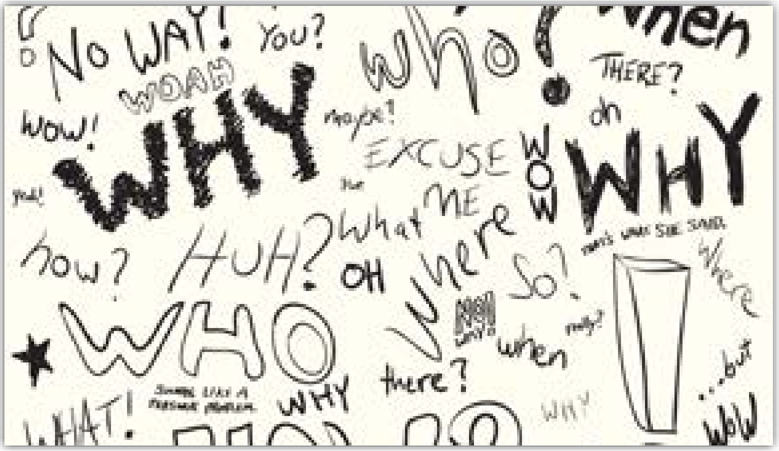
## Chapter 4

# Who’s Who in the Healthcare System

# Why are you involved?

This post shows the importance of educating all members of the healthcare team as to the role, function, and value of having a nurse advocate involved in your care.

[https://nursesadvocates.com/why-are-you-involved](https://nursesadvocates.com/why-are-you-involved)



In 2021 I returned to taking on clients as a nurse advocate after a prolonged medical leave of absence. I returned to being a nurse advocate after a life-changing experience where I was the patient. The main takeaway from my experience was how hard it is to be a patient.

As I emerged from my journey, I decided to return to active practice and help those in need, especially those who had limited resources and needed help to advocate for themselves. My role for my clients is to coordinate care, break down barriers, and find the resources my patients need to address their healthcare needs. I work with all members of the healthcare team, the insurance company, and others patients and caregivers encounter in their medical care.

What I found since returning is that being a nurse advocate, a case manager, or any of the other titles for professionals who do this type of work is that it is HARD WORK. The healthcare system is frustrating, challenging, unfriendly, expensive, and dangerous if there isn't someone to watch out for the patient.

While working with a man with liver disease, a nurse in one of his doctor's offices asked me why I was involved. I stopped for a minute, as her question took me by surprise. Then I explained I was involved to help the patient coordinate his care, set up and attend appointments, and help him understand his care plan. I was involved because his son lived out of state and couldn't go to the various appointments with him. After each doctor's visit, I would call or send him an email update so he could stay aware of what was going on with his dad. I am the "boots on the ground" person to help the man and his son during a complex time.

After I finished my explanation, she said, "Oh, I never knew people could have someone like you work with them." I replied, "Yes, this field is becoming more and more popular because people realize they need help as the healthcare system is complex, fragmented, and built for the healthcare system—not for the people who use it."

I work with those who are sick, have complex cases, and who have a hard time making an appointment. They're trying to understand what each of their doctors is saying, even as the doctors' schedules don't allow them time to sit and get to know their patient. I am the one who says, "Doctor can you stay for a minute while Mr. X asks you a question?" I am involved to give the patient and their family members a voice in a system where many don't have time to listen. I ask the patient and the family what they want and help them communicate that information.

I am involved to assist one person at a time, navigate a complex and fragmented healthcare system when they're not feeling well and don't have the energy to work in a difficult a system. *That* is why I'm involved!

As I have shared frequently, EVERYONE can use an advocate when they're thrust into the complex world of healthcare.

# Knowing who’s who in the healthcare system

This post reviews who’s who in the confusing healthcare system. Patients and their families are the only constant members of the healthcare team, and they need to make sure they take an active role in the system.

https://nursesadvocates.com/knowing-whos-who

Entering the healthcare system is challenging, intimidating, and stressful. Here I share insights into who’s who and who you can depend on to answer your questions and help make your hospital experience better.

**The Hospitalist:** If you’re in a hospital, the doctor who will follow you during your stay is called a hospitalist. Today, few primary care doctors make rounds in the hospital. The hospitalist is the doctor who makes rounds and writes the orders that the team will carry out. He or she will write your discharge orders. The hospitalist will coordinate your care with other specialists and members of your team.

Your hospital records should be sent to your primary care doctor, but in case they are not, you should take good notes while in the hospital to communicate the information to your primary care doctor. As I’ve mentioned previously, having an advocate, a member of your family, or a trusted friend with you when you’re a patient in the hospital is a good practice. Your loved one can help you keep up with what happens when you are in the hospital.

**Specialists**: During your stay, you may see one or more specialists to help the hospitalist understand your condition. You may need to follow up with the specialist after discharge, depending on what was found. It’s crucial to make sure these doctors are part of your insurance network to avoid out-of-network charges. Usually, the hospital will check this, but it’s good to ask the specialist if he or she accepts your health insurance to prevent surprise billing. If they don’t, you will have to let the hospitalist know this so they can find another specialist to see you or get an exception from your insurance company to ensure your insurance company pays the specialist’s bill.

**Nurses**: Nurses are the backbone of the healthcare team, and they can be an essential source of information for you. Talk to your nurses and let them know if you have questions or don’t understand something. They usually can help you better understand things, or they can get the hospitalist or specialist to come to your room and answer your questions. Nurses know how “the system” works, so talking to them will help you better understand it. Nurses spend the most time with patients and are up-to-date with the plan of care and how things should go.

**Charge Nurse**: Most nursing units or floors have a charge nurse who oversees the nursing staff. If you have a problem with the staff, the condition of your room, or the services provided, the charge nurse is the person who can help resolve issues. If your nurse can’t answer your questions, you can ask to speak with the charge nurse, who should help address the problem.

**Nurse Case Managers/Social Workers**: Today, most hospitals have case managers/social workers to work with patients and their families. These professionals work with your team to coordinate your care and plan for your discharge. These professionals are also in touch with your insurance company to make sure you meet the criteria to be in the hospital at the correct level of care. You can let your nurses know that you want to talk to a case manager if you have questions about your insurance or your discharge care plan. These professionals can help break down barriers and allow you access to resources to meet your needs.

**Pharmacists**: Pharmacists are essential members of the healthcare team, and they can help you understand your medications and how they're helping manage your conditions. It is vital to let your team know all the medicines you are taking, including supplements, to have an accurate understanding. Be sure a pharmacist does a "medication reconciliation" at each transition of care to make sure you're on the right medications and they're working as intended. Before you go home, ask a family member or friend to bring all your medications so the pharmacist is aware of what you are taking and can "reconcile" prior medications with any new ones you are to take after discharge. Once your medications are reviewed, you can update your medication list. Make sure you share your updated list with your primary care doctor and your specialists so they can make changes to your record.

**Therapist**: During your hospital stay, you may see various therapists, including a respiratory therapist, physical therapist, occupational therapist, speech therapist, dietitian, or other specialist. These professionals can help you understand your conditions and how you can manage them to reach your highest level of well-being.

The bottom line is: There are a lot of people you will encounter during a hospital stay. You'll only see some while you're in the hospital, and others will continue to see you after you've been discharged. Make notes so you remember who's who. Ask for their business card so you can keep a record of who you saw and when. Keeping good records will help you be an active part of your healthcare team. Talk to each professional and never be afraid to ask questions. Doing so will help you be informed and can prevent mistakes or medical errors.

I hope this post helps you have a better idea of who is who on your medical team. Remember, you and your advocate are the only constant members of your healthcare team, so take notes and be involved in YOUR care. Doing this will improve your hospital experience and help you be the best you can be!

# Care coordination: We can do better

I recall an experience that made me realize we have a lot of work to do to help those with chronic medical conditions like diabetes live a healthy life.

https://nursesadvocates.com/2433-2

I once spoke at an amputee support group meeting, where I shared tips on How To Be Your Own Best Advocate. I have given this talk several times, and each time the audience expresses surprise that they have such an essential role in their health and healthcare.

The talks are interactive, and I love to hear the stories people share. Many times, the stories are sad. As a nurse, case manager, and nurse advocate, I feel disappointed because it shows how lost people are when they find themselves in the complex healthcare system.

At this meeting, there were four men and one woman. As we talked, I learned they all had experienced lower leg amputations caused by diabetes. All were middle-aged and seemed to be educated and reasonable people. Most in the group had one of their legs amputated, but one man had had both legs amputated.

As I left the group after the presentation, I wondered what went wrong in their treatment that caused them all to have amputations. Today we know so much about the treatment and management of those with diabetes. How did these people fall through the cracks?

One article I read showed that each year, approximately 200,000 non-traumatic amputations occur. African Americans are four times more likely to experience diabetes-related amputation than whites. In the United States, someone is diagnosed with diabetes every 17 seconds, and every day, 230 Americans with diabetes will suffer an amputation. Throughout the world, it's estimated that every 30 seconds a leg is amputated, and 85% of these amputations were the result of a diabetic foot ulcer.

These numbers are staggering. If we're honest with ourselves, they point to a failure in care coordination. We can and must do better. We need better patient education, and we have to break down barriers for patients, like access to safe, quality care. We have to learn how to better coordinate care for everyone, as the stakes are too high not to.

If you know someone with diabetes or who is at risk for diabetes due to obesity or hypertension, encourage them to:

1. Find a doctor they like and can establish a relationship with. Doing so will help them visit the doctor for their check-ups and reach out when issues arise.
2. We have to teach people to be proactive to recognize problems and get treatment to avoid setbacks and limit the complications that occur.
3. Empower patients to follow a reliable treatment plan that is tailored to their individual needs.
4. Encourage each patient to learn as much as they can about their diabetes.

5. Recommend a course taught by a Diabetic Nurse Educator. Such a course will help the patient learn how to manage their condition, recognize complications, and know why it's important to report problems immediately.
6. Help patients set health goals that will meet their lifestyle.
7. Help them learn how to keep their blood sugars under control, the importance of getting annual eye checks, and doing daily inspections of their feet.

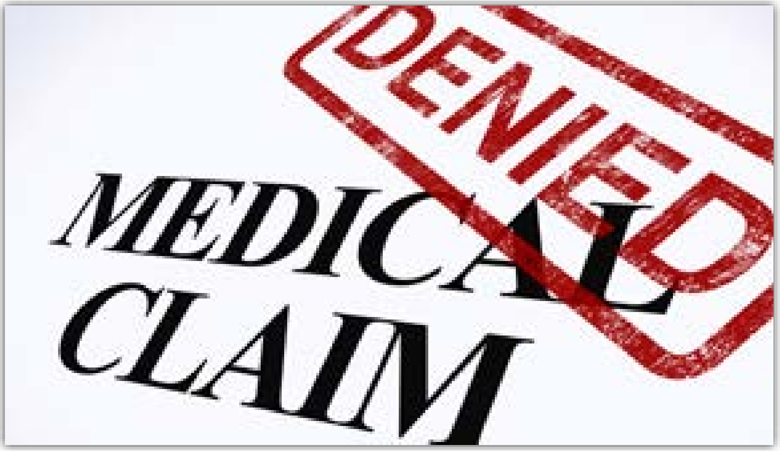
People can live with diabetes, but they need help and close monitoring. They need to pay close attention and listen to their bodies. Living with a chronic condition is not easy, but with a competent healthcare team and self-management, you can do well and avoid complications.

Nurses, case managers, care managers, patient/health advocates, social workers, and all members of the healthcare team are at the center of changing the status quo. Seek their help because you are important.

# Appropriate use of health resources

I wrote this to educate consumers on appropriate use of healthcare resources. There is data to show that when consumers are involved in their care, they make better decisions and costs are lower.

https://nursesadvocates.com/appropriate-utilization-of-healthcare-resources



In this post, I explain the processes that are in place today to ensure appropriate use of healthcare resources.

In the past physicians were not questioned as to the care decisions they made. This is because physicians had the power to write anything they felt the patient needed to treat their medical issues. Once written, the patient's insurance company would pay the bill without much oversight. As a result of this practice, there was massive over-utilization of services that caused healthcare cost to skyrocket.

Today, there are utilization requirements in place by the payer that providers, physicians, and the hospital systems need to follow for payment to be authorized by the payer. These rules may seem burdensome to providers and most consumers, but they have helped control costs while ensuring the care provided is based on scientific evidence, is timely, and is in line with the patient condition. These practices have also been shown to have slowed healthcare spending and improved the quality of care provided.

The first requirement from the payer is for providers, physicians, and hospitals to supply evidence that supports their request for high-cost treatments such as diagnostic tests, medications, home care, rehabilitation, or other services. The evidence should follow the national guidelines that payers and providers all have access to.

This system allows for a review process by the managed care organization. The physician ordering the treatment must provide their rationale and evidence to support the care before moving forward. The hospital utilization review nurses or the office staff from a physician's office email the information or send via a secure fax line to the managed care company to begin the review process.

Once a request is received by the insurance company, a utilization review nurse reviews the orders and documentation against the national guidelines. If the information meets the criteria, the orders are approved. If the information does not meet the criteria, then the information is sent to a physician on staff at the insurance company who does their own review and makes a determination. Again, if the physician feels the information meets the guidelines, the care is approved. If not, the reviewing physician will issue a denial. Nurses cannot issue denials; only physicians can make these determinations to deny care.

Managed care organizations have to follow strict timelines to ensure these reviews are done on a timely basis and do not to hold up treatment. If the treatment is denied, the insurance company has to explain why and give the physician or hospital the rationale in writing.

As you can image, this is a difficult and controversial process. It is often argued that the ordering physician who knows his patient should be given the benefit of the doubt. To assist, a process called peer-to-peer review is part of the utilization review process. The theory behind this process is that the treating physician and the managed care physicians doing the review can take a minute to talk to each other about the patient, the rationale for the orders written, what the treating physician is looking for and what the expectations are for the treatment. When this type of discussion occurs, most denials are overturned unless there is strong evidence against the proposed care. Most managed care physicians want to give the treating physician some leeway in treating their patients, so the peer-to-peer review is an important part of the process.

There may be some restrictions put on the treatment to allow for a trial period, but this would be spelled out in the approval letter. Consumers and hospital case managers should encourage the peer-to-peer discussion, as it will assist the process and is a way to advocate for the patient. This process also shows the importance of clear and supportive documentation that defends the plan of care.

If the denial is issued, then the treating physician, the hospital, or the patient has the opportunity to appeal the decision. Again, there are strict rules around this concept that all have to follow.

If an appeal is requested, the insurance company has to have a physician review the case—a physician who is an expert in the field of the patient's condition and has had no connection to the physician who did the initial review. This is so the review process is independent and objective.

Once the physician asked to do the appeal has an answer, a telephone call and a letter are sent by the managed care company to the ordering physician. If a hospital or another type of provider is involved, they would also get notice of the decision, as well as the patient. If the appeal overturns the denial decision, generally the managed care company abides by the decision.

If the appeal upholds the denial, then generally, the physician would seek a new course of treatment or the patient has the option to pay for the service if they (and their doctor) feel the course of care is needed. Also, if there are additional avenues for the physician/patient to take, that information would be detailed in the letter from the insurance company.

As a patient, you have a right and responsibility to participate and be involved in all of these discussions. You can and should encourage your doctor to send in detailed information on your case to provide an explanation as to why care is needed, take part in the peer-to-peer discussion, and appeal the decision if needed. As these processes take time, many physicians do not go through the process unless the patient requests that the doctor advocate for them.

While these processes take time, they're in place to ensure that the care recommended is based on the most up-to-date scientific evidence to meet your needs.

All of this information is included in the member handbook your insurance company provides, so take the time to familiarize yourself with these procedures so you're aware of your rights. Physicians and providers are also well aware of the rules and the process as part of their agreement when they become contracted to a managed care network.

Again, the utilization management process is in place to ensure the care you receive is: 1) safe, 2) evidence-based, 3) appropriate for your condition, 4) based on your current condition, 5) timely, 6) cost-effective, and 7) approved by the insurance company if an approval process is required before treatment is rendered.

The role the patient plays in the utilization review process is important, as your input can help your doctor better understand your goals and help them plan your care to fit your needs. Patients should:

- Understand the treatment recommended.
- If there's more than one treatment option, all options should be explained to the patient by the ordering physician so the patient is given the opportunity to choose the option that best meets their goals. This process is known as shared decision making.
- Understand how the treatment being ordered will make a difference in your care.
- Understand what the tests show or what the treatment will do to improve your care.
- If you don't get the treatment, what are the consequences to your condition or life?

- Are there complications associated with the treatment to be aware of?
- What costs will you, the patient, be responsible for if the treatment is approved? You may have a co-payment to make if/when the treatment is approved.

Your doctor should be able to answer all these questions. If your physician does not provide the answers to any of these questions, you should question the plan of care, as having answers to these conditions is critical.

The more you understand your care and treatment options, the more likely you are to ask questions, learn, and receive care that meets your goals. When physicians and other members of the healthcare team work with their patients, it leads to improved health care outcomes as well as lower cost of care.

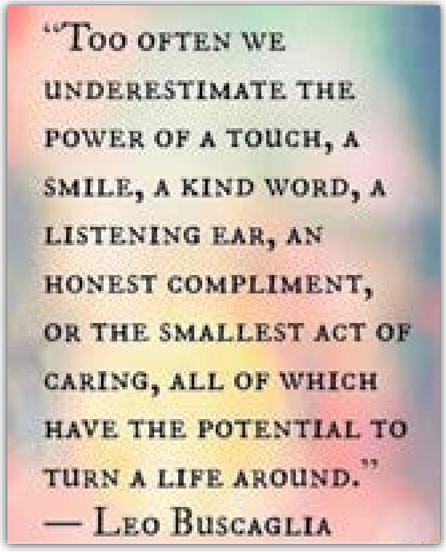
# Chapter 5

# Why Everyone Needs a Patient Advocate

# It’s the little things that matter

A short story on how the little things matter to our patients and ourselves.

https://nursesadvocates.com/its-the-little-things-that-matter



“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”
— Leo Buscaglia

Recently I worked with a 95-year-young woman as a nurse advocate. Initially, she was very sick, weak, and sad. Over time, her medical team worked to correct her problems, and she improved significantly.

I am seeing another side of my patient as her personality emerges. I see her as a strong, independent woman who lives alone and is awake, alert, and oriented. She is aware she is frail and takes precautions to be safe. During the COVID-19 pandemic, she took the necessary precautions to be safe.

Now that she’s improving, we have pleasant conversations while going to doctor appointments. We also review what we want to know when we see the doctor. I am there as her nurse advocate, but most of the time, as I sit there with her, I am proud of how she advocates for herself.

You may wonder why I'm still involved when she's now doing so well. I am in place to assist her and help her organize and coordinate her ongoing care, as at times she feels it's too much for her to handle. I also am in a place to give her sons updates and keep them informed as issues arise. They rely on me as I am local and can mobilize quickly if somethings happens when they are both out of town. This gives them peace of mind.

I am realizing my role is more than the clinical skills I bring or the ability to coordinate complex care. I also bring the little things that help a person feel safe and cared for.

I recently came across this message from author Leo Buscaglia that I feel sums up my role: "Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which can turn a life around."

Yes, I am there as a nurse, as an educator, and as an advocate, but I am also in place to help my patients realize someone cares for them as a person.

If you are a member of the caring professions, keep this saying with you to remind you that, in addition to the important clinical work you do, it's also important to remember the little things.

# Everyone needs an advocate when they're thrust into the complex world of healthcare

A post about my own experience needing a caregiver and advocates.

https://nursesadvocates.com/everyone-needs-an-advocate-when-they-are-thrust-into-the-complex-world-of-health-care

As a nurse, I was always the one who was looked to when a healthcare challenge emerged. But when I was diagnosed with a brain tumor in November 2014, it was my husband who stepped in as my caregiver and healthcare advocate.

Corky and I have been married for 29 years, and he has always been my biggest supporter. He has always been the levelheaded member of our family. He always remains calm and respectful regardless of the situation, so he handles challenges much better than I do. He has no healthcare experience except for the stories he has heard from me and my friends over the years. Yet, when the time came, he stepped up, took charge, and was my advocate through the most challenging time of my life.

When I got sick, he did his best to listen to the doctors and ask questions so he understood what they were telling him about my diagnosis, treatment options, and prognosis. I was cognitively not able to participate, so Corky had to make decisions regarding my care and my life. Luckily, we had discussed our wishes so he knew what my wishes were, and he advocated for me.

When my diagnosis was made, he realized it was a very serious situation. He called a good friend of mine and a fellow nurse case manager to help him understand what he was being told and what the options were. My friend, Marilyn, was there to listen, support, and help as she could. She came to the hospital when we met with the neurosurgeon who explained the plan of care. It was at this meeting when Marilyn and Corky both realized I was not in the most appropriate hospital for the severity of my condition.

As my advocate, Marilyn stepped into her case management role and took to the phones until she found a neurosurgeon at the University of Miami who agreed to take my case. I was discharged from the small community hospital and went to see the neurosurgeon the next day.

I was very sick when I met with the neurosurgeon at the University of Miami. He recognized this and admitted me right away so I was in a safe place and could be stabilized. He scheduled the brain biopsy for the next day so they were sure of the type of tumor I had and could decide on the plan of care. Once the pathology report was back, I was referred to a hematologist who specialized in the type of tumor I had. I saw him right away and he ordered aggressive chemotherapy be started. I truly believe this expedited care saved my life.

My husband took another piece of advice from Marilyn that proved helpful throughout my treatment. She suggested he get a binder to keep all track of all my records. Corky did this and collected reports, test, scans, lab work, and notes that detailed my care and recommendations from everyone who saw me along the way. He took his own notes on what he was told by the various professionals who cared for me. He brought that binder to each appointment, and when I was an inpatient in the hospital, he had the binder with him every day. When the team made rounds, he listened to what they said and asked questions. Many times, he was able to produce a report or a lab test they needed but was not readily available in the chart. They would thank him and proceed with the orders.

Having Corky at my side and armed with useful information saved me from getting a test repeated or experiencing a medical error. Many times, the team would be talking about a direction they wanted to go and my husband would mention something my doctor had told him. He asked that they check with the head hematologist before writing the orders. Each time, they came back and said they were going to follow the current plan of care as directed by the hematologist.

Once I improved and was able to participate and ask questions, my husband stayed involved and reminded me of various things that I was not aware of. He was always patient, respectful, and willing to listen. Yet he didn’t hesitate to ask a question or suggest that a resident, nurse, or another member of the team check with the attending physician to ensure that what they suggested was in line with my plan of care.

My experience reinforced to me that every patient needs an advocate when they are thrust into the complex world of healthcare. It is evident to me more than ever that the healthcare system is set up for the system itself, and not for the patient or their caregivers. Patients need to have someone by their side who is there for them.

So much information comes at you at such a rapid pace, at a time when you are least able to comprehend it. Having an advocate allows another person(s) to hear the information, ask questions to help to clarify things, and be able to repeat things over and over so you and other family members can understand what is going on, so all are clear on the plan of care being designed on your behalf.

Advocates can be family members or friends. For most of us, this is all we need, another set of eyes and ears. But for a complex situation, having a professional patient advocate is important.

Advocates are objective members of your healthcare team and are in place to ensure you have a voice, are able to ask questions and do research to look at alternatives that might match your plan of care so they meet your goals. Advocates address barriers and help ensure your care needs are met. Independent patient advocates are paid privately by the patient or the family, so they are not under the restraints of the organization for which they work.

There are hospital advocates who are also able to help. They are in place to represent you and ensure your needs are met when you or a loved one are in the hospital. Generally, they have the autonomy from the hospital leadership to be your voice and to advocate for you when issues arise. In addition to independent and hospital advocates, there are others, such as billing advocates, who help you review medical bills, address denials by your insurance company, and negotiate bills so you can set up a payment plan that protects you. There are also housing advocates who can help find alternative living arrangements when needed.

There are several ways to find an advocate. Many advocates have websites, so they show up when you do a simple Google search. When considering an advocate, take the time to talk to them to make sure you are both clear on what they can do, as well as whether they have the experience to meet your needs.

Keep in mind advocates do not provide hands-on care, but rather do research and meet with your healthcare team to understand the plan of care to ensure it meets your individual needs. They ensure you have a voice in your care and are at the center of the healthcare system.

Here are some resources to help you learn about the emerging practice of patient advocacy.

- Patient Advocate Certification Board: Advocates come from a variety of backgrounds. The Patient Advocate Certification Board has now certified over 800 professionals as Board Certified Patient Advocate.
- Advoconnection has a database where you can enter your zip code to find a patient/health advocate.
- Health Advocate X: A national organization educating consumers and advocates.
- Aging Life Care Association: The Aging Life Care Association (ALCA), a nonprofit association with over 2,000 members. The mission of the organization is to lead the community of Aging Life Care Professionals™ through education, professional development, and the highest ethical standards.

- Patient Advocate Foundation: A not-for-profit organization that helps people find help by eliminating obstacles in accessing quality healthcare.
- National Association of Healthcare Advocacy (NAHAC): The professional organization for healthcare advocates dedicated to the improvement of patient outcomes through continuing education, promotion of national standards of practice, and active pursuit of policy change that lead to excellent person-centered healthcare. You can input your zip code to find an advocate in your area.
- Greater National Advocate: An online database of patient/health advocates. Enter your zip code to find an advocate in your area.
- My Care Alliance: An organization that offers membership to a variety of professionals who are in place to help a variety of people. Enter your location to find an advocate in your area.

Today, there is a call for all of us to be active members of the healthcare team. Most of the time, we can do this ourselves, but when you have a healthcare challenge that is complex and life-changing, you need an advocate to be there for you!

# Advocacy around the world

This post shows the emerging practice of patient advocacy, because healthcare is complicated wherever you live!

https://nursesadvocates.com/patient-advocates-around-the-world

I want to share a project I've been working on. It revolves around the area of patient advocacy. Today, patient advocacy is an emerging field in healthcare. If you have been a patient or have had a family member or friend who is a patient, you know that navigating the complex healthcare world is challenging, costly, and many times, unsafe. Having a patient advocate who is by your side can relieve stress, allow you to focus on your family and friends, and give you peace of mind so you can get through each day.

I have had the pleasure over the past ten years to learn and participate in this emerging practice. At first, I did not understand the difference in what a patient advocate did compared to what I did as a nurse and a case manager. Over the years, in talking to people in patient advocacy, I learned more about the practice.

But it wasn't until I became a patient in 2014 that I understood the real value advocates bring.

Simply, patient advocates are in place for the patient and the family. For the most part, they are independent of the payer and the healthcare system. This allows them to focus on the patient's needs separate from the politics of the various entities that make up the healthcare system. Advocates interact with the healthcare team to meet the needs of their clients and navigate the healthcare system. Having an advocate makes a difference and allows you to see outside of the very rigid healthcare system.

I have often said that the healthcare system works for the healthcare system, not the people who use it. Today, people (you and me) are paying more and more of our healthcare costs. So being an active member of your healthcare is critical to ensure your care meets your goals. Patient advocates are there for you, and they work to make sure your wishes/goals are known. Patient advocacy is an emerging practice around the world because healthcare is complex regardless of what country you live in.

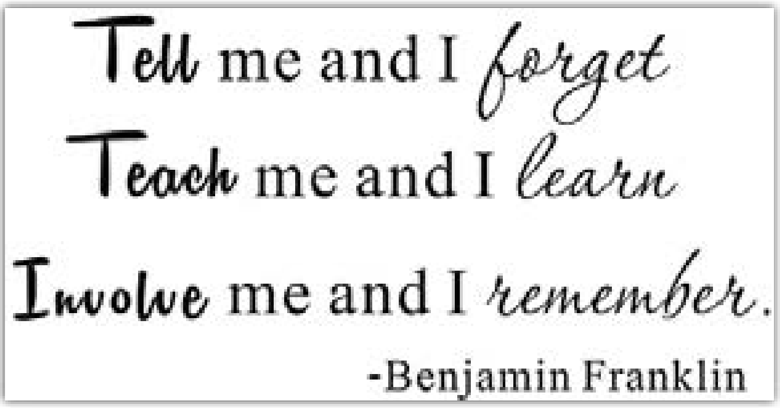
Take some time and watch each of the videos on The International Conference on Patient Advocacy website: https://icopaconference.com/patient-advocacy-around-the-world/

You'll get a feel for how the practice of patient/health advocacy is emerging around the world. Feel free to share the link with others.

# The teachable moment

This post shares two experiences I had that taught me the importance of meeting patients where they are. In this case, the patient was me. Two of my caregivers used teachable moments to help me understand my care and reach my goals.

https://nursesadvocates.com/the-teachable-moment



Tell me and I forget
Teach me and I learn
Involve me and I remember.
-Benjamin Franklin

Today, finding that “teachable moment” is so important. Life is all about learning and gaining a better understanding of the events taking place so we can make choices that enrich our lives. This could not be truer than in healthcare.

Today, there is a focus on ensuring the patient is the central member of the healthcare team. Evidence shows that the more we engage the patient, the better the outcomes will be.

Everything we do as healthcare professionals revolves around the patient, so it is in our best interest to educate and empower them so they’re informed, educated, and know the choices they have regarding the treatment they receive. Many healthcare professionals are cognizant of this and are taking the time to educate and empower patients and their families.

I'd like to highlight two examples of "teachable moments" I experienced during my healthcare journey. Each helped me be a more informed patient so I could help myself heal and better participate in my care.

The first example came when I was in the hospital getting my 5th round of chemotherapy. My nurse for the day came in and introduced herself. We talked as she updated the whiteboard in my room with her name and how I could reach her if I needed her. Then she turned to me and asked me what my goals were for the day. I looked at her for a minute, as no one had ever asked me that question before. She explained to me that she wanted to help me reach my goals, but to do that she needed to know what they were.

I thought about it and told her that I wanted to get a shower. I also said that I wanted to take a walk so I could get out of my room for a little while. These were not easy goals to achieve, as I was hooked up to IVs and needed help to get into the shower since I was very weak. The nurse was not put off by my requests, however. She said, "Okay, let me check on my other patients and then I'll be back so we can get started on helping you meet these goals."

When she returned, she got me ready to take a shower. She gathered towels and put a chair in the shower so I could sit down once I got in there. I asked her about the IVs, and she said, don't worry, we can unhook you for a short time. She then went and got a shower sleeve that she put over my arm where the PICC line was so it wouldn't get wet. This allowed me to wash myself, and it felt great having hot water run over my body. I was even able to wash my hair!

Once done, I put on a clean gown, which felt great. She reconnected the IVs, and I got back into my bed to clean sheets. My nurse and the aide were able to change my bed while I was in the shower.

After I had rested for a while, the nurse came back and asked me if I was ready for my walk. She got me up, and we took a short walk up and down the hallway. It was fun seeing the other patients and staff I passed. Each said hello and asked me how I was doing. I felt good and I was glad I had achieved my goals for the day. I was grateful to my nurse for asking me what they were.

The second teachable moment occurred during a conversation my husband and I had with the pharmacist, who was a member of my oncology team. It was Week 4 of my chemo treatment. My hematologist had just told us that my tumor was

GONE. Both my husband and I were in shock, as we had not expected that news so early in my treatment.

As my team was making rounds, the pharmacist stayed behind for a minute to ask me a question. After I answered him, he asked me if I had any questions for him. I took the opportunity to ask him how the tumor could be gone. I told him we were happy and grateful, but we didn't understand how it could happen after just three treatments.

He explained to us that the protocol I was on was meant to work fast—if it was going to work. As a result, the team expected the tumor to shrink or be gone after the 3rd round of treatment, which is why they scheduled an MRI after the 3rd round. He explained that in my case, the tumor was very receptive to the chemotherapy, and as a result, the tumor was gone. His explanation helped me understand and realize there was a science to the treatment I was receiving. His explanation made me very grateful that I had been referred to this hematologist, who'd specialized in the type of tumor I had for years and had developed a protocol to treat the tumor type. I was also grateful that my tumor was receptive to the therapy and was GONE.

I asked the pharmacist about recurrence. He said, "There is a high probability of recurrence, but that is why the doctor will watch you for a few years." I asked him, "If the tumor returned, would I get the same type of treatment?" He said he didn't know and that my hematologists would determine the course of treatment if and when the tumor recurred. For now, just relax, he said.

These two examples showed me the importance of finding the teachable moment and taking advantage of it by educating and empowering a patient. Each situation allowed me to be involved and better participate in my care. It showed me that, by setting goals and asking questions, I could better understand my care and help myself heal.

If you are a patient reading this, I hope these words empower you to ask questions. Each member of your team is there to help you to understand your diagnosis and the plan of care in place to treat your condition. If you have questions or want to do some things that will help you feel better, don't hold back. Taking care of *you* is the most important thing they do.

If you are a healthcare professional reading this, I hope it helps you realize there are teachable moments in every encounter. Please take the time to engage your patients. Ask them questions and learn who they are and how they are feeling about themselves and their conditions. These conversations lead to those teachable moments that help your patients and their caregivers be involved in their care.

## Chapter 6

# Comments from Readers of the Blog

In this chapter, I'm sharing a sampling of the comments I have received on various blog posts. As a writer, you often don't know if you're reaching people and sharing information that will make a difference. That's why I value the comments I receive from readers. They let me know my topics are striking a chord. I also like to see how readers learn from one another from the comments made. It shows the articles have stimulated communication and engagement.

**Debbie Loomis** on September 28, 2021, commenting on Knowing Who's Who

Crucial info Anne, thx so much! (and Bonnie I love your idea of asking visitors to write down their name/instructions—I plan to "steal" this idea!)

**Dana Deravin-Carr** on September 21, 2021, commenting on Saluting the Unsung Heroes of Healthcare: Caregivers

Once again Anne, you bring pride and professionalism to our role every time you step up to the plate and bat a home run! How wonderful that Troy's family is available to support him; having loved ones nearby makes all the difference for him leading a life of quality. Thank you for being the gift that you are!

**Jody Luttrell** on August 10, 2021, commenting on Don't Assume

On point as always Anne! I think this all ties into health literacy and helping patients be "better" patients. As I go with my elders to appointments, I find that you only get 5-10 min with a doc and most of that they will spend on social chit chat and say everything is fine!

**Cathy Bowers** on August 10, 2021, commenting on Don't Assume

Anne, your topics are so important to share with your readers—both as individuals and advocates assisting them.

Excellent points Bonnie, re: being prepared—agree with checking with medical provider prior to your appointment to confirm the purpose of the visit and if the provider has all the reports in hand.

Even if I get a text or email reminder of the appointment, I still try and call the day of to make sure the provider is available and if the staff can let you know if they are running on time. Recently a colleague twice had an appointment with Provider A and then when they arrived was told Provider B would see her. She declined both times to see Provider B and went elsewhere.

**Trisha Torrey** on August 13, 2019, commenting on Focusing in on Patient Centered Care

Anne – your advice is some of the best advice for any professional: If you want to complain about something, be sure you have one or more suggestions for how to improve it. Leaving a complaint on the table without a suggestion labels you as a complainer. Making a complaint with good improvement suggestions labels you as proactive—a thinker and a leader. Thanks for this!

**Linda DeBold** on August 13, 2019, commenting on Focusing in on Patient Centered Care

Great article - should be given to every nursing student!

**Julie Moss** on August 11, 2019, commenting on Care Coordination: We Can Do Better.

On every point, so very true. As healthcare personnel, whether clinical or not, we owe it to patients to educate them on the value of advocating for themselves. It's a significant pivot in the system to allow patient and provider lanes to cross and ultimately integrate, but one that has tremendous potential to improve quality of life for patients and quality of care from providers.

**Sharon Cavone** on February 18, 2018, commenting on Nine Tips to Get Patients Actively Involved in Improving Their Health Outcomes

What great insight! Relationships only survive when parties involved remain engaged—whether we are talking about couples or patient & healthcare team. Care coordination is one way for to positively affect the status of an ongoing relationship in healthcare. Always listen to the patient & educate, educate, educate.

**Dr. Rachel Silva**, NP, on November 8, 2015, commenting on What To Do While Waiting

Well, the next time I am forced to wait, I am thinking of this post, Anne! Unfortunately, sometimes in life we are forced to wait and have time to reflect on our life and future goals. Life is too busy, we all need to be able to enjoy the moment, even while “waiting.”

**Kelly Moed**, RN, on November 12, 2015, commenting on What To Do While Waiting

Great perspective. I will never look at waiting the same and plan to spread this post and the great concepts to my coworkers and patients in the hospital. Change the world a little at a time. Thank you.

**Lori Grosse** on November 18, 2015 commenting on What To Do While Waiting

Every facility’s patient satisfaction staff should read your post, especially the portion that talks about the value of demonstrating simple courtesy through frequent communication. Great points!

## Chapter 7

# Subscribe to the Nurse Advocate blog for free

If this special report was interesting to you; if it made you think or empowered you to learn more and better yourself, make sure you are signed up to receive Nurse Advocate in your inbox each Tuesday morning.

If you have a challenge you want me to cover, let me know. Also, if you have a story you want to share, please tell me, as I do have guest writers from time to time.

**NOTE: Subscribing is a two-part process.** First, when you are on the website at www.nursesadvocates.com, a pop up will appear on screen. Simply put your name and email address in.

Second, once you hit the Subscribe button, you will get an email to confirm your email address. Do that, and you are on the list! You can opt out at any time. Your email address is safe and is never sold to a third party.

# Thank You

Thank you for reading this special report. I hope you will share it with your family, friends, and colleagues. If you have any questions or comments, please email me at allewellyn48@gmail.com.

Anne Llewellyn, RN-BC, MS, BHSA, CCM, CMF, CRRN
Nurse Advocate
954-254-2950
Read my blog at www.nursesadvocates.com/blog

Credits
Author: Anne Llewellyn, RN-BC, MS, BHSA, CCM, CMF, CRRN, Nurse Advocate
Editing and Design: Andrea Morris, A Ripe Mango Marketing, aripemango.com