

A Survivor's Compass

Empower yourself with an **L** advocate's attitude as you navigate your own cancer journey.

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Most of us go through our adult lives aware that there are many things over which we have no control. But the words “you have cancer” can leave you reeling with the reality of this awareness. Following the initial shock, many patients and caregivers attempt to harness what control they do have by gathering information or by talking to friends or family who make them feel heard. Others withdraw, taking time to adapt to this new reality. Regardless of how each person chooses to cope with the initial news of a diagnosis, many will continue to struggle with the sense that they have been thrown into foreign waters with no map, compass, or directions in their native language.

So what can you control? Your attitude and your approach to living a full life. As a survivor, this can make all the difference in your experience. The following are some basic guidelines designed to create a framework that can help you develop your own unique style of self-empowerment and self-advocacy. These insights are

intended to encourage you to create a life-preserving, healthy, and positive attitude as you navigate the new terrain of a cancer diagnosis.

1. A cancer diagnosis is not an emergency.

A cancer diagnosis is a crisis, and it needs to be dealt with in a timely manner, but try not to allow the crisis to force you into rushed decisions. Making careful, well-thought-out choices about interventions and treatments is one of the most important things you can do during the initial weeks post-diagnosis. Many survivors say that they wish they had taken more time to think out their early options, instead of simply reacting to the pressure and the stress of their diagnosis. Unless there is a true health crisis (such as respiratory problems, seizures, or other complications), treatment decisions can be made at a pace that is comfortable for you. Remember: this is your diagnosis, your life, and your timeline.





2. Introduce your healthcare team to the person behind the diagnosis.

If you allow yourself to think of yourself as “just another cancer patient,” you will become just that. Do not allow your diagnosis to overshadow who you are as an individual, and do not let it take over your identity. You are a person living with cancer, not a cancerous person. A diagnosis does not define a person. People are multidimensional beings with diverse and unique characteristics and experiences. It is essential that all individuals be perceived and understood holistically. Make yourself memorable to every clinician you meet: make sure everyone knows your name during visits with providers, wear something distinctive, discuss a current event, interject humor, or find some other way to connect on a personal level. Do your best to take some time to talk about yourself—who you were before cancer—in addition to your diagnosis and treatment.

3. Enhance your self-awareness.

This experience is really all about you—but do you really know who you are? We are all unique creatures on this planet and there is no “one size fits all” formula for dealing with a cancer diagnosis. Take the time to think about who you are and ask yourself questions about what type of people and behaviors you respond to best. Be

honest with yourself: When interacting with others, do you tend to be sensitive, opinionated, withdrawn, polite, impressionable, assertive, defensive? What resonates for you? How do you cope best? Self-awareness can be one of your greatest tools throughout your cancer diagnosis. Knowing who you are and who and what you respond to best will be of great value to you with the many complex decisions you will encounter—whether it’s choosing a doctor, seeking support, or handling friends and family.

4. Communication is a two-way street.

How do you communicate? Do you tend to be forthcoming, withholding, succinct, verbose, humorous, serious? What is your listening style? Take some time to really think about how you communicate and relay these insights to your healthcare team. Try starting the conversation with phrases like this: “I can hear you best when you...”; “I don’t understand you when you...”; “I like to ask a lot of questions...”; “I’m not comfortable with...”; “I make jokes when I’m nervous...”; “I shut down when...”. If you have the opportunity, try to select healthcare providers who best match your communication style. If you have no choice, be sure to educate those you will be collaborating with, including your family and friends. Knowing yourself is key, but if you can’t communicate that unique self to others, you risk being misunderstood or not heard at all.

5. Adopt a second language.

What don’t you understand? Could it be those foreign-sounding clinical terms, multisyllabic drug names, or fancy-sounding acronyms that clinicians throw around? You are not expected to instinctively know the language of the new world you’ve entered; but now that you’re here, take the time to learn and understand all the medical terms used in discussing your unique situation. Do not hesitate to ask, ask, and ask again every time you hear a term, a phrase, or an acronym that you don’t know. It is the clinician’s responsibility to explain everything to you in terms you understand. This may be his or her two-hundredth case with the same treatment protocol, but if it is your first time hearing it, get clarification.

6. Ask for what you need when you need it.

No one is ever prepared to deal with a cancer diagnosis, and it is never a sign of weakness to admit that you need help. Reach out to the professionals. They are specially trained and not as emotionally clouded or biased as family members can be. Find the social worker at your treatment facility; he or she can be your best ally. Be specific about the resources you need and keep asking for more as your situation changes (because it will change). There are an abundance of resources available today (many listed in this magazine), and you are entitled to more than you probably know about.

Don’t be afraid to ask questions of your healthcare team. You’re not being a nuisance by asking for what you need. You have the right to object to what is suggested, to seek a second opinion, to admit that your pain is not being managed effectively, to report that your fatigue is getting worse, or to let your team know that you don’t want to take a particular medicine because of the side effects. Your needs will change along the way, and it’s important to let others know. Being able to advocate for yourself might just save your life.

7. And let everyone know what you don’t need.

Most caring people in your life will have good intentions, but they don’t always know what is helpful or how to best support a person diagnosed with cancer. It’s up to you to enlighten them; don’t allow them to behave in ways that are bothersome to you. If they are using language or expressions to define your experience that you don’t like, let them know. Not every cancer patient wants to be thought of as engaging in a “battle”; not all survivors want to be told countless times to “stay strong” or “be positive”; and

certainly no one wants to be told terrible stories about others’ negative cancer experiences. If you find yourself feeling frustrated by others’ words or behaviors, remember that you don’t have to be polite and tolerate what doesn’t help you. Correct and inform your friends, family, and healthcare providers. You do a disservice to yourself and to those around you when you don’t express your needs openly and honestly.

8. Spend energy living forward, not backward.

The first instinct of many newly diagnosed patients and their loved ones is to search for a cause of their diagnosis. Where did this come from? Did my behavior or lifestyle cause this cancer?

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Though natural, this tendency depletes precious energy. The time spent looking back and trying to discover a cause does not help your current situation, nor does it contribute to your healing. If you’re feeling anxious or fearful, seek out whatever professional or personal interventions work best for you. You can then free

up valuable energy to focus forward on a hopeful future with improved health and increased quality of life.

9. Set boundaries and delegate.

These are seemingly simple concepts, but many people find setting boundaries and delegating—both forms of self-care—very challenging. Become aware of areas in your life where you can delegate more and tighten up some boundaries. Utilizing these self-care skills can provide you with a means to manage and oversee some control in your life—you owe it to yourself to master them. When you practice them on a regular basis, it frees up more energy and time for healing and life-affirming experiences that truly benefit you.

10. “What worked before may not work now.”

I heard this statement shared at a conference by a genuinely engaging woman who has survived two different cancers. Truer words were never spoken. A cancer diagnosis changes who you are; it is a holistic transformation in that it affects the whole you. The status quo of your life has been radically altered along with multiple aspects of the previous you who existed outside the world of cancer. The myriad changes that follow a cancer diagnosis alter the way you view the world and yourself. Nothing is the same as it was before because you are not the same. If you're finding

that certain attitudes, behaviors, people, or activities no longer enhance your quality of life, consider making changes that honor the new outlook you have of yourself and the world around you.

Most important: Start from wherever you are!

Living with cancer is not a linear process. Your experience, feelings, moods, and needs can shift from day to day, hour to hour, and minute to minute. Check in with yourself: What is most pressing today? Where I am right now? Try not to judge your situation; acknowledge that where you are is a temporary state. Give yourself permission to throw out previous priorities and embrace new ones. This is an area where you can exercise some control by assessing your needs and deciding what's most important to you. Maybe today's priority is about fun; maybe it's about making a treatment decision. Once you know what you need and want, formulate short-term goals and long-term goals, then reevaluate them on a regular basis. Make sure that they are not too ambitious so you don't set yourself up to fail. You may be able to meet some of your goals on your own; others may require some assistance—recognize the difference and take action. In situations that feel out of control, self-awareness, recognizing your own needs, and self-advocating can help you feel empowered. ✨



Need Help Navigating? Reach Out.

At a time when you need it most, a Cancer Navigation Consultant™ can be that reliable ally who can provide information, guidance, and support. If you or someone you care about has been diagnosed with cancer, reach out for help.

PEG'S Group, a private, independent practice of Cancer Navigation Consultants,™ provides personal education, guidance and support for people affected by cancer. PEG'S Group offers a variety of diverse services individually customized to meet the needs of each client. Services include counseling, home visits, and telephone and e-mail consultations.

PEG'S Group is located in the New York City area, but the organization will work with you to accommodate your needs no matter where you live. To learn more about PEG'S Group, visit www.pegsgroup.com, call (718) 246-PEGS [7347] for a complimentary initial consultation, or contact company founder Kathy Gurland at kathy@pegsgroup.com.

