

What is advocacy?

Advocacy, or the act of pleading for, supporting, or recommending, plays a significant role in the success of someone diagnosed with cancer. Different types of advocacy tend to be more of a priority for a cancer patient, depending on the length of time since a diagnosis. All three have played an important role for me; in my job as a nurse, my experience as a volunteer, and my life as a cancer survivor. They can also have a tremendous impact on a person's healthcare, treatment, quality of life, and possibly even their prognosis.

The three main types of advocacy that I will discuss and provide information on are the following:

Self-Advocacy- the act of being **assertive**; being an **active and informed** participant in your own cancer treatment and healthcare.

Example:

For someone who has been diagnosed with cancer, the scheduling of tests, along with the waiting for impending results, can bring about increased stress and anxiety. Many of us more "experienced" cancer survivors have learned that there are opportunities for "self-advocacy" that can significantly decrease that anxiety time and stress. Communicating well is an advocacy skill that can be learned and very useful at any time from a diagnosis of cancer. Instead of the routine, the conversation of getting a medical appointment might actually be something like this:

Radiology Receptionist: "I'm sorry, but I don't have an opening for at least two weeks, to schedule you in for your ultrasound."

You, the Self-Advocate: "Well, two weeks or more will not work for me. I will *definitely* need a *much* sooner appointment. Would you please check the schedule again?"

Radiology Receptionist: "But, ma'am, you don't understand, I have nothing available for two more weeks. You will just have to wait."

You, the calm, but assertive Self-Advocate: "Yes, I'm sure that it is busy, but you see, ***I don't wait well!*** I know that Dr. McDreamy and I were both expecting a much quicker appointment. Please see what changes you can make to provide us with a better service."



Radiology Receptionist: "Well, you'll have to give me your phone number, and I'll see what I can come up with."

Community Advocacy- the act of **supporting** an idea or cause/ or **volunteering** for an organization.

Example:

As the Bozeman team captain for the **Montana Komen Race for the Cure®** (Fundraiser for breast cancer) in Helena several years ago, I opted to implement a bus in order to engage as many participants as possible. We aptly called our transportation system, "The Breast Bus." I was then able to get more of our local area advocates to **support our cause**. We definitely made an impression with our sign on the back of the bus that said, "Breast or Bust!" ☺

Political Advocacy- the action of working **to promote legislation**, supporting a cause or proposal.

Example:

It didn't take much more to convince a Montana legislator that he should sign our "Cancer Promise" document when the following occurred in Washington, D.C.:

Several political advocates, or Ambassadors, who were working with the **American Cancer Society's Cancer Action Network**, were waiting for our Montana legislator in his office to discuss why he should sign our "Cancer Promise," document. Most of the experienced advocates had indicated that this particular legislator would be quite reluctant to sign anything that may hold him accountable to any legislation regarding cancer research funding or prevention. However, it didn't take any convincing when I noticed a box full of chewing tobacco in his office while we were waiting for him to meet with us. After I inquired about the existence of this box to his "health" aide, the young man responded emphatically that they were "generously donating it to the troops in Iraq!" The only thing that was left to say to him was that "Our Montana legislator should know that the American Cancer Society Ambassadors were *not* impressed by hearing that we were providing our troops with known carcinogens, and if he wanted to make a better impression, he would kindly sign the "Cancer Promise." We received the good news two hours later, that the document had been signed!

So, stay tuned to learn how to fight back! All of these types of advocacy are an opportunity for anyone to help themselves and others.... even if you don't have a Dr. McDreamy!

Although advocating for patients has always been an essential role in my career as a nurse, it is also necessary for a patient to be an active participant in their healthcare. Since my diagnosis of breast cancer, I have come to realize that we, as healthcare

providers have enabled patients to rely on us. In fact, because we have allowed patients to depend on us, we have taken away one of the most important aspects of their treatment, ***self-advocacy***.

Many patients believe that they will be deemed a “difficult” patient, if they question their healthcare providers, especially if they ask for a second opinion. I continue to hear from patients that they do not want to “bother” members of their healthcare team “because they are so busy.” Healthcare is a ***service***, and you, the patient, are the ***consumer***. As a consumer, you must understand the service you are receiving, if you are to make ***informed choices***, and to know whether or not you are getting ***quality care***. In cancer care and survival, ***knowledge is power!***

Because most cancer patients are not knowledgeable about how to self-advocate at a time when it is crucial, cancer treatment centers offer a ***social worker or nurse*** on staff for this purpose. However, be aware that even though their role is to teach and “guide” you to be a self-advocate, it is important that you become as actively involved as possible in the process.

Some organizations are aligning cancer survivors- those who have had a similar diagnosis- with a newly diagnosed patient. The ***American Cancer Society*** offers their ***Reach to Recovery*** program for this purpose. Trained volunteers meet one-on-one with women who have recently had lumpectomy or mastectomy surgery, to share what was helpful, or not, during their experiences of cancer treatment. Again, their role is a process to teach you opportunities for self-advocacy, not to tell you what you should do for your particular situation.

The Wellness Community (TWC) promotes self-advocacy through the ***Patient Active Concept***. This concept supports the idea that *“People with cancer who ***participate*** in their fight for recovery from cancer will improve the quality of their life and may enhance the possibility of their recovery.”* “Combining the will of the patient with the skill of the physician - a powerful combination in the fight against the common enemy - cancer!”-- Harold Benjamin, PhD, Founder of The Wellness Community

To learn more about the Patient Active Concept, see the website for TWC at: www.thewellnesscommunity.org

You can also learn to become a better self-advocate for your healthcare through ***support groups***. This might include any local cancer support group whose members will exchange information about their experiences with each other, including how they have learned to become a self-advocate.

Retreats or camps, such as ***Cancer Family Network, Reel Recovery®, Casting for Recovery®, Camp Mak-A-Dream, or Mending in the Mountains®***, offer another excellent resource to connect with other cancer people. Retreats and camps will often have knowledgeable speakers to help train participants about topics of self-advocacy.

Educational forums such as this email forum through **Cancer Family Network** and the **American Cancer Society's "I Can Cope,"** teach patients how to become more involved and knowledgeable, which will help them actively participate in their treatment. For those located in rural communities, support groups can be available online by connecting with other cancer patients in chat rooms. There are many options online to connect with others who are dealing with a cancer diagnosis and treatment.

Example:

At **Mending in the Mountains®** (a cancer retreat for women diagnosed with cancer), we had a panel of women speak to the group. These women were what we titled, "Remarkable Survivors." They all shared with the other participants, their stories of what they felt contributed to their longevity after being given a poor prognosis for their type of cancer. Although we heard consistently about ways that each woman learned to be an exceptional self-advocate, we discovered that their self-advocacy had amazingly improved their quality of life, as well.

The National Coalition for Cancer Survivorship @ www.canceradvocacy.org offers an online self-advocacy training program called **The Cancer Survivors Toolbox®**. It teaches about, communicating more effectively, making decisions, negotiating, standing up for your rights, and other self-advocacy topics.

Learning to be a better self-advocate can make you feel **empowered** about your cancer treatment and experience, which leaves you feeling less like a "victim" of your disease.

Community Advocacy

When I finished my chemotherapy for breast cancer after six, long months, I was disappointed that I didn't feel as excited as the rest of my family. Even though I was grateful to be done with the side effects of the drugs, my fear of recurrence of the cancer created even more anxiety for me. Because I wasn't *actively* fighting the cancer, it seemed like I was just supposed to wait to see if the cancer would return. It wasn't long after that, I decided that I wasn't going to just wait around for cancer- I was going to do something- anything!

I had read a book called **The Okinawa Program**. It was about a study done for a period of 25 years that looked at a group of people, the Okinawans, who have among the lowest mortality rates in the world from a multitude of chronic diseases of aging, including cancer. As a result, these people enjoy not only what may be the world's longest life expectancy but also the world's longest health expectancy. The diet and lifestyle of this group of people offered amazing information of why these "Centenarians" had such a long life expectancy. (81.2 years vs. 76.8 in the USA) The authors provided concrete evidence that adopting "the Okinawa Way," pays off significantly in terms of tacking more productive years onto our lives. Although much of the information on diet, exercise, and meditation wasn't entirely surprising to me, what did spark my interest



was that **-doing volunteer work, and building a solid network of friends and family-** was a key factor in the daily lives of the Okinawans. It seems that volunteering, or **community advocacy**, was good for their health!

“...there’s another side to helping those less fortunate than you besides pure altruism. You just might be making yourself healthier in the process. Studies show that people who help other people are consistently in better health and are more able to overcome life-threatening crises and diseases.” –The Okinawa Program by B. Willcox, C. Willcox, M. Suzuki.

Volunteering in your community is a type of advocacy that can help others, while helping yourself at the same time. ANYONE can volunteer! It is just a matter of figuring out what you enjoy doing, how much time you have to offer, and then providing that “gift” to your community. Although, you don’t have to align only with cancer affiliations- you may choose to help with your church, your schools, or a local service organization, such as a Lion’s or Rotary Club. The opportunity to heal through nature is especially important for cancer patients, so offer what you can to help with your community trail systems or adopt-a-highway. A local Bozeman artist, diagnosed with cancer, now offers to share her skills and talent with children at the library. You can even provide volunteer time in your own home, such as knitting hats for cancer patients or babies in the nursery. Or, you can help others through their cancer treatment by attending a local support group or online chat group to share your experience about what has been helpful or not. It’s not about *what you do*, as much as it is about providing *some kind of advocacy* to help others.

Benefits of Volunteering:

Several research studies are now looking at the health benefits of volunteering. From improving mental health to longevity, the results are numerous. To read more about these studies check out the following website:

<http://www.worldvolunteerweb.org/news-views/news/doc/volunteering-helps-improve-health.html>

Opportunities for Community Advocacy:

Churches

Community or Hospital Cancer Center

Food Bank

Fundraising Options- walk, run, bike, hike, skip, jump, etc.

Health Fairs



Humane Society

Local Hospital

Retreats or Camps

Salvation Army

Schools

Service Organizations- Lions, Optimist Clubs, Rotary

Skilled Nursing Facilities (Nursing Homes)

United Way Organizations- Big Brothers, Big Sisters, Boys & Girls Club, etc.

Tips for Volunteering:

- When you volunteer, make sure that you let the organization know what aspect of volunteering you enjoy, or things that you might enjoy doing.
- Ask about receiving training, which should include information about the organization, your responsibilities, and resources for any questions that you might encounter.
- Let them know how much time you have to offer, and don't feel guilty about saying **no**, when asked to offer more!

Remember that many volunteers are scheduled just like regular staff, so be sure to give as much advanced notice as possible for any changes, to allow them to find a replacement. If you are currently in treatment and your reliability is unpredictable, offer to help with something that doesn't depend on scheduling.

For those who live in a more rural location, there are many options to help, including connecting with others through online support groups or starting a cancer support group in your small community. I joined a strategic planning committee shortly after my treatment ended to bring a community cancer center to Bozeman- now we have **The Wellness Community-Montana** and **Mending in the Mountains®**, a nationally-affiliated cancer center, and a cancer retreat for women, because of thousands of volunteer hours that many of us offered. Even though it has been rewarding to see so many cancer patients and their families benefitting from our community advocacy, it was even more amazing to realize how much *I had received* from volunteering!

And there are always the- walking, biking, running, or skipping ☺- fundraising options associated with any number of cancer related organizations which anyone can get involved and enjoy exercising.

So, as you have hopefully learned regarding community advocacy, ***"It is better to give, because you will receive!"***



Political Advocacy

"The ultimate conquest of cancer is as much a matter of **public policy**, as it is a scientific and medical challenge."
-John R. Seffrin, PhD, CEO of ACS CAN

Political advocacy is the opportunity for ALL of us to be heard by our legislators in order to change or implement policies that we support. Many issues affect cancer prevention and care, therefore it is important that we be informed and then stay updated on cancer-related legislation. For those who might think that this sounds overwhelming, many national organizations and nonprofits have made the process easy, yes *easy*, for those who have internet access.

Political advocacy first peaked my interest a few years ago when I realized that the **American Cancer Society (ACS)** had a sister organization called the **Cancer Action Network (CAN)**, (a 501c4 nonprofit). It was specifically developed so that the ACS would be able to lobby without the restrictions that limit a 501c3 nonprofit. I learned that CAN volunteers and staff were actively involved in helping to promote the Clean Indoor Air Act in Montana. The opposition of this Act, with significantly more money, and supposedly more power to lobby, were the Big Tobacco companies. I saw the opportunity to help a great organization promote the issue that was near and dear to my lungs. Thus began my role and commitment as an **American Cancer Society's Cancer Action Network Ambassador for Montana**. Now my family says I have a "Dr. Laura attitude"- Preaching, Teaching, and Nagging.

How can politics be easy?

American Cancer Society, Komen Foundation, Lance Armstrong Foundation, and National Coalition for Cancer Survivors all have registries that will update you on forthcoming cancer-related issues. These organizations will email you with alert, or action notices about when to contact your legislators about a specific bill or policy. Usually a formatted letter is provided for you to contact your officials, with which you may add your personalized story prior to forwarding on. Most actions or alerts take less than a few minutes to complete and send. These advocacy organizations will update you on any pertinent information or bills, and also regarding how your specific legislators have voted. This gives you the ability to hold them accountable for what they have said they will do. In the past, I have received response emails from Sen. Baucus, Sen. Tester, Rep. Rehberg and my state officials. Most ARE interested in your concerns and want to hear from you! Remember, they all work for YOU.



Ways to advocate on political issues:

- Write a letter to the editor of the newspaper
- Sign up for the email action/ alert
- Ask candidates about their stand on cancer-related policies
- Register to vote
- Vote!
- Attend public forums and debates involving candidates

There are many political issues that impact cancer patients and their families. In fact, since so many organizations and people have become involved, a number of policies have been implemented or changed to help fight against cancer.

Cancer-related issues:

Access to quality, affordable healthcare
Cancer prevention
Environmental Risks
Funding for cancer research, programs, screening and treatment
Healthcare rights
Insurance reimbursement for screening and treatment
Pain and symptom management
Quality of Life
Standards of care
Survivorship
Work discrimination for cancer patients

It is an exciting political year with changes in our country's leadership forthcoming. So how do you know which candidate to vote for in the June primaries and again in November? Be aware of the many opportunities to stay informed and learn more about who supports the cancer specific issues. **Please note:** Most organizations or nonprofits will **not** endorse any candidates or parties, but rather are issue specific.

Examples of Questions to Ask Political Candidates:

"What would you do to decrease cancer deaths in this country?"

"Would your administration be in favor of a national ban on smoking in public places?"

"If elected President, would you work to significantly increase funding to the NCI and CDC?"

How do you feel about a national health care plan?

Political Advocacy Resources:

If you check out any of these websites, you will find that it is very easy to become involved and make a difference:



American Cancer Society's Cancer Action Network (CAN)

<http://www.acscan.org>

Lance Armstrong Foundation's LIVESTRONG ARMY

http://www.livestrong.org/site/c.khLXK1PxHmF/b.2729893/k.89FD/LIVESTRONG_Army.htm

National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org/>

Susan G. Komen Foundation's Champions for a Cure

<http://cms.komen.org/komen/PublicPolicy/ChampionsfortheCure/index.htm>

Did you know that Montana has a coalition that was established to address the cancer issues specifically affecting Montanans? It is called the **Montana Cancer Control Coalition**. This involves a group of individuals (over 150) and organizations from around the state who have developed a plan, called the **Montana Comprehensive Cancer Control Plan**. This plan addresses cancer-related issues for Montanans. For more information or to get involved, check the website at:

Montana Cancer Control Coalition

<http://www.dphhs.mt.gov/PHSD/cancer-control/cancer-control-index.shtml>

Summary of Advocacy

Although the topic this past week was provided to be applied to those diagnosed with cancer, I hope that you have all realized that this information can be helpful for any disease or anyone. **You don't have to wait for cancer to be an advocate in your own healthcare.**

From **Self-Advocacy** to **Community Advocacy** to **Political Advocacy**, ALL are vital to the health and well-being of a cancer patient. I am so convinced of this, that I believe each oncologist should hand out a prescription that says **Advocacy- take for LIFE!** (We all seem to be much more compliant with prescriptions that our doctors give us.) It is definitely one of the cheapest, yet most powerful regimens we can follow for our own healthcare. Now go do the right thing..... ☺