

The Power of Advocacy

In cancer survivorship, advocacy is a continuum. It may begin at the personal level, but it may broaden to encompass group or organization advocacy—and later, public advocacy efforts.

Personal Advocacy

At diagnosis and during intensive cancer treatment, self-advocacy is a way of taking charge in an otherwise intimidating environment of diagnostic tests, surgery, radiation, chemotherapy, and doctors' offices. From supporting yourself with information about your diagnosis, to seeking second opinions, to locating resources for identifying and obtaining support, to knowing how to ask the right questions—your personal empowerment can mean the difference between maintaining a positive future outlook and feeling helpless.

The one to five years after a cancer diagnosis is a time of reentry and reevaluation of your life. It is during this time that cancer survivors realize that their lives will never be the same, and many survivors seek out other survivors with whom they can identify.

This life transformation calls for another type of self-advocacy. With the underlying idea that they “want to give something back,” in gratitude for their survival, many survivors seek out avenues to share their experience with others. This sharing of knowledge—the veteran helping the rookie—is what the survivorship movement is largely about. When

occurring in the context of a self-help group or within a professionally facilitated support group, this passing of wisdom from a more seasoned survivor to a newcomer provides a strong foundation for people who have had cancer to play a more active role in making decisions that will follow them the rest of their lives.

Advocacy for Others

Having been successful in exchanging information with others who share a cancer experience, survivors can extend their advocacy efforts to the larger community. Through networking with other persons in their area, survivors can learn more about specific issues. Supported once again with valuable information, cancer survivors can go on to tell others their shared experiences and advocate for changes that can have a broad impact on survivorship.

One of the easiest and most satisfying ways to advocate for others is to speak at the local community level—to church and civic groups, to medical students and physicians, oncology nurses, social workers, and others—to educate them about the complex interpersonal and

psychosocial issues that dominate survivors' lives. This public speaking becomes a testimony that affirms one's survival, defies many of the myths and stigmas about cancer, and perhaps reaches others who are silently struggling with similar issues.

Public Interest Advocacy

The exponential growth of the survivorship movement increasingly is realized by the many long-term survivors who go on to become professional survivor advocates. These individuals have taken their learned experiences from diagnosis, through treatment and recovery, and become advocates participating in the national cancer survivorship movement. Particularly notable among them are those who have effected change in public policy, including appropriations for cancer research; those who have pressed for more survivorship research; those who have given public witness testimony at both the local and federal levels of government; and those

who have contributed to the body of knowledge about living a better quality of life after a diagnosis of cancer, either through professional journals or the popular press. By telling "one's story," including through print and broadcast media, the net is cast much wider.

As people with a history of cancer recount their stories in the community and to the media, they become recognized experts on the compelling issues that have impacted their lives and the lives of the community of survivors with whom they have become involved. Depending on one's vocation, avocation, or other life circumstances, the interest one takes in sharing this experience is limited only by the desire to speak up—whether it is survivor to survivor in support groups, in the workplace, before state legislators, or to Congress. Advocacy is an invaluable skill set that can empower people with cancer and can maximize the quality of their own survival as well as that of others.

Excerpted from "Advocacy: The Cornerstone of Cancer Survivorship," by NCCS President & CEO Ellen Stovall & Elizabeth Johns Clark, PhD

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