



## Patient Advocacy

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To cite this article: Diane Van Ostenberg (1995) Patient Advocacy, *Oncology Issues*, 10:6, 5-5, DOI: [10.1080/10463356.1995.11904569](https://doi.org/10.1080/10463356.1995.11904569)

To link to this article: <https://doi.org/10.1080/10463356.1995.11904569>



Published online: 28 Sep 2017.



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**D**espite obstacles to patient advocacy initiatives from current efforts to restructure health care financing in the United States, the ACCC Board of Trustees has valiantly identified patient advocacy as one of its top five priorities for 1995/1996. Professionally and personally, I couldn't be more supportive of this strategy.

Generally speaking, I see the advocacy process as a combination of dedication, understanding, and perseverance: dedication to those for whom the advocacy is being undertaken; understanding of the larger system in which the advocacy is being conducted; and perseverance to maintain a full court press despite momentary disappointments. I believe perseverance is the fuel for the advocacy engine.

Who better exemplifies this tenacious quality than Sir Winston Churchill? One of my favorite stories about this great Brit is his commencement address to an Oxford University graduating class. Armed with his trademark cigar, cane, and top hat, Churchill approached the podium to a standing ovation. As he readied himself to speak, carefully placing his top hat on the podium, Churchill gazed solemnly at the expectant crowd. At last he shouted, "Never give up!" Several seconds passed, and Churchill rose to his toes repeating, "Never give up!" There was a thunderous silence as the great man reached for his hat and cigar, steadied himself with his cane, and left the podium. With those three words, he had said it all.

Persevere we must as well. Only in the past decade has advocacy been recognized as a legitimate strategy for influencing the policies that shape the delivery of oncologic care in the community setting. As we move into the arena of managed care, oncology health providers are being confronted with a complex array of issues that go far beyond a patient's clinical visit. We are interacting across disciplines within complex delivery systems, often witnessing the restricted access of patients to the cadre of highly trained interdisciplinary cancer care providers. Other issues such as conflict of interest, the exclusion of payment for patients on investigational clinical trials, and lack of reimbursement for state-of-the-art cancer therapy are having a deleterious effect on our ability to deliver quality care in the community setting.

Late effects, those changes that are measurable months to years after cancer treatment and are unique to the oncology patient, require the availability of expertise and specialized resources to enhance the likelihood of rehabilitation and survivability. Finally, insurability and so-called preexisting condition limitations may threaten

even limited insurance coverage of cancer patients with certain diagnoses for significant periods of time. In these scenarios, the ability of patients to maintain financial autonomy is severely compromised.

Nevertheless the ACCC Board is committed to assume a leadership role in patient advocacy at the community and state level in addition to augmented efforts on a national level. To that end we are seeking support for a "President's Educational Grant." The grant will sponsor a Patient Advocate's Workshop with the intent of developing a detailed plan for mobilizing the cancer coalitions in the U.S. Although supportive of the specific disease groups initiatives, the Board endorses the concept of a community's responsibility to address the health care needs of all individuals dealing with cancer and to ensure access to whatever excellence is available for all cancer survivors. Larger coalitions will be more powerful and will have a greater impact on influencing health policy for cancer survivors.

In November I traveled to Washington, D.C., to represent ACCC at the Cancer Leadership Forum sponsored by the National Coalition for Cancer Survivorship (NCCS). A principal mandate of the First National Congress on Cancer Survivorship was to set an agenda that will guide the NCCS's advocacy initiatives toward ensuring comprehensive, quality cancer care across all stages of cancer survivorship. Following this forum, I also represented the Association at the first National Cancer Summit sponsored by the Association for the Cure for Cancer of the Prostate. The meeting's theme was "Twenty-five Years Later: Redefining the War on Cancer—Countdown to Cure." It was a unique opportunity for our Association to collaborate with other advocacy groups and professional organizations that represent the interests of the 1.25 million people who will be diagnosed with cancer in 1995 as well as the more than 8 million cancer survivors in our country.

While the mechanism for change—advocacy—is relatively new to us, its track record of initiating and directing public policy in other areas is well known. Despite the obstacles, we must forge ahead together, and as Churchill so succinctly said, "Never give up!"

Diane Van Ostenberg