



The Cancer Survival Toolbox

Audiotape Resource

Debra Thaler-DeMers

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The Cancer Survival Toolbox Audiotape Resource

by Debra Thaler-DeMers, B.S.N., R.N., O.C.N.

A cancer diagnosis is a life-altering event. Although it has been many years since hearing my own diagnosis, that moment is frozen in time for me. It is as if my existence is divided into life "B.C." (before cancer) and "A.D." (after diagnosis). At that moment I was vaguely aware that my oncologist's lips were moving. To this day I have no idea what was said after the word "malignant." My mind was consumed with that one word and had stopped processing other information.

My experience is not unusual among the eight million people living with a cancer diagnosis in the United States. In a 1998 survey of 569 cancer survivors conducted by *Coping with Cancer* magazine (March/April 1998), less than half of the respondents believed that they were able to communicate effectively with their health care providers or had the skills necessary to make appropriate decisions or solve the problems they faced following their diagnosis.

Since its inception in 1985, the National Coalition for Cancer Survivorship (NCCS) has promoted self-advocacy for cancer survivors. Using an unrestricted educational grant from Genentech BioOncology, NCCS invited the Oncology Nursing Society and the Association of Oncology Social Work to participate in a collaboration that would combine the skills and experiences of cancer survivors

Debra Thaler-DeMers, B.S.N., R.N., O.C.N., is vice president of the National Coalition for Cancer Survivorship in San Jose, Calif.

and oncology professionals in developing *The Cancer Survival Toolbox*.¹ The *Toolbox* is a set of audiotapes that teaches specific skills and provides information on self-advocacy for the cancer survivor. It was designed with the intent that physicians would give the toolbox to their patients.

The skills taught in the *Cancer Survival Toolbox* are communication, information seeking, decision making, problem solving, negotiating, and self-advocacy. Case examples for each skill illustrate and reinforce the material. Although developed for the newly diagnosed cancer survivor, the skills are applicable at any time in the survivorship continuum. In the current climate of health care management, it is essential for survivors to have the skills necessary to obtain quality cancer care. The *Toolbox* equips survivors to stand up for themselves, which in turn instills a sense of some measure of control over their treatment. "Finding Ways to Pay for Care" is its newest tape, designed to address those specific issues faced by the millions of individuals who have no health insurance or whose insurance does not cover the high cost of cancer care.

Upon first being introduced to the *Toolbox*, patients often exclaim, "I wish someone had told me about it earlier!" Newly diagnosed survivors frequently feel overwhelmed as they face the drastic physical, emotional, economic, and spiritual changes that accompany a cancer diagnosis. In addition, they are meeting a new physician on whom they must rely in what could be a life-threatening situation. In giving

a survivor the *Toolbox*, the physician acknowledges the psychosocial aspects of a cancer diagnosis, which helps the survivor and at the same time strengthens the doctor-patient relationship.

The audiotape format was selected for several reasons. Audiotapes can be used in a variety of settings and are relatively inexpensive to produce. They can easily be translated into other languages for survivors whose primary language is not English. Survivors who have difficulty reading printed materials (due to a low literacy level or impaired visual acuity) also benefit from the audiotape format. Audiotapes can be replayed as often as necessary and shared with family members and significant others.

The *Cancer Survival Toolbox* in audiotape format is available in English and Spanish and can be obtained free of charge by calling 1-877-TOOLS4U or accessing the NCCS web site (www.cansearch.org). Written versions of the *Toolbox* are available on the web site in both English and Chinese. The written format for the Chinese language overcomes the need to translate the tapes into the many dialects of the Chinese language.

The initial consultation is an ideal time to introduce survivors to the *Cancer Survival Toolbox*. It is also an excellent resource for the oncologist's office or infusion center. The *Toolbox* tapes, along with cassette players and headsets, can be made available for patients' use during treatment and also as a resource throughout the survivorship continuum. ■