

Going Forward

Taking cancer survivorship to the next level.

We are both survivors. We started our “survivorship” experience at the same time, roughly 35 years ago. One of us survived as a patient, the other as an oncology nurse. Yet both of us remember that time well, when the term *cancer patient* was synonymous with *victim*, when the five-year prognosis was grim, and when the treatment process itself was so ghastly that people chose a sure death rather than endure it.

The patient survivor (ELS) remembers the angst, the uncertainty over whether she would live to see her son start school. The stage and extent of her disease were of concern to her physicians, who were not optimistic. And she vowed that if she survived for two years, she would devote whatever was left of her life to addressing the issues we all now call *survivorship*: quality of care, *equality* of care, and the quality of life, as well as employability, insurability, fertility, and sexuality.

The oncology nurse (CDH) remembers “pushing chemo,” pulling rabbits out of a hat to minimize the nausea, the vomiting, the infections. She moved the chemotherapy room around to keep people from vomiting in anticipation of entering a room they’d been in before. She hid from patients at the grocery store so they wouldn’t see her and vomit.

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Thirty-five years later we’re both part of the National Coalition for Cancer Survivorship (NCCS). This group of cancer survivors and their providers met in Albuquerque, New Mexico, in 1985 to share the experience of

Long-term survival
creates new challenges.

living with cancer. Since that initial meeting, the public has become aware of the impact of cancer on patients and their family and friends. And treatment advances have dramatically increased the number of people who live for many years beyond their diagnosis. Symptom management has improved; many survivors now complete therapies that are far more aggressive and toxic than their predecessors. But long-term survival creates new challenges—those pertaining to medical and psychosocial sequelae that are undertreated and rarely recognized. As nearly 11 million survivors seek follow-up care and present with longer-term medical and life challenges, the need for a systematic approach to surveillance and chronic care has become evident.

Over the past decade the Institute of Medicine (IOM) has studied the state of cancer care in the United States. As early as 1996 it concluded that care is fragmented and in many cases poorly coordinated. In November 2005 the IOM released its most recent report on survivorship, entitled *From Cancer Patient to Cancer Survivor: Lost in Transition*. The report (which was coedited by ELS) highlights the need for survivor care planning

that emphasizes the transition from active treatment to long-term follow-up. It urges providers to address with survivors the changes that occur over the long term. Additionally, the IOM calls for development of “survivorship care plans,” posttreatment summaries that encompass surveillance, rehabilitation, late and long-term effects, legal protections, and psychosocial services. The nursing profession was cited as a vital component of survivorship care planning. Because oncology nurses already provide educational and other resources to survivors, this recommendation seems logical. Even so, a recommendation only becomes practice when it’s embraced by those providing the care.

To that end, in November 2006 *AJN* convened a meeting of 40 representatives of nursing, social work, and advocacy groups to focus on the role of nurses in survivorship care planning.

The NCCS represented survivors at that meeting. We know firsthand that nurses play a critical role in survivorship. We depend on you throughout the cancer experience to guide us, to provide needed care, information, and support. You help survivors cope and are present during many important transitions. We hope you will help make survivorship care planning standard care. We believe you can make a difference, just as you have ensured better symptom management during treatment. We urge you to read the report by Haylock and colleagues on page 58 and consider how you can incorporate a “prescription for life” into your practice. ▼



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