National Coalition for Cancer Survivorship: Advocacy for Quality Cancer Care

By Ellen Stovall

When the founders of the National Coalition for Cancer Survivorship (NCCS) came together 22 years ago, they sparked the survivorship movement that focused on adapting to life with, through, and beyond cancer, rather than treating a diagnosis as a death sentence. Crucial to this idea of survivorship is advocacy—taking responsibility for your cancer care through open communication, shared decision making, and active participation in your care. Today, NCCS is the oldest survivor-led advocacy organization, advocating at the federal level for quality cancer care for all Americans and empowering cancer survivors to advocate for themselves. To ensure that anyone diagnosed receives quality cancer care, NCCS strives each day to include the voice of survivors throughout the cancer experience, whether that means asking questions of your healthcare team or speaking out in arenas where healthcare policy is determined. This long-standing and primary emphasis on advocacy for better care sets NCCS apart from other important cancer organizations with which we frequently collaborate.

Quality care becomes increasingly important as cancer becomes more of a chronic condition managed for longer periods of time. Identifying the need for better care, the Committee on Quality of Health Care in America and the Institute of Medicine’s Crossing the Quality Chasm: A New Health System for the 21st Century defines quality care as safe, effective, patient-centered, timely, efficient, and equitable. Achieving such care is a goal of the Cancer Quality Alliance, which is cochaired by NCCS and ASCO. For more than a year, Cancer Quality Alliance Work Group 1 has been working to develop the report with the proposed title “Blueprint for a Better Cancer Care System,” a set of case studies to illustrate optimal cancer care in today’s medical system. “Blueprint for a Better Cancer Care System” is intended to serve as a teaching tool for a wide audience, including all healthcare practitioners involved in cancer care, medical educators, patients, and the general public.

Care plans, consisting of treatment plans, treatment summaries, and follow-up care plans, are mechanisms to facilitate effective communication between physicians and survivors about safe, effective, patient-centered, timely, efficient, and equitable—quality—cancer care. NCCS and ASCO have worked closely on developing care plan templates, which are consistent with key recommendations of the 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition.

To further encourage care planning, NCCS and ASCO also support the Comprehensive Cancer Care Improvement Act, which includes a number of proposals that would advance a system of integrated cancer care and improved communication between patients and their healthcare teams regarding treatment options and follow-up care. By reforming Medicare reimbursement, enhancing training of professionals who treat cancer survivors, and testing and expanding model systems of integrated care, the Act would advance a system of quality, comprehensive cancer care. The bill has been introduced in both the House (HR 1078) and the Senate (S. 2790) and has received widespread support within the cancer community.

Working together with survivors, physicians and healthcare providers, and other organizations in the cancer community, NCCS harnesses the power of survivorship to make the promise of quality care a reality for all Americans diagnosed with cancer.

Ellen Stovall is President and CEO of the National Coalition for Cancer Survivorship.

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References

1. Committee on Quality of Health Care in America and Institute of Medicine: Crossing the Quality Chasm: A New Health System for the 21st Century defines quality care as safe, effective, patient-centered, timely, efficient, and equitable.

