Cancer Experts Issue First Guidelines For Survivors, Rare Cancer

By Susan Jenks

For the first time, the National Comprehensive Cancer Network (NCCN) has issued clinical guidelines for treating the nation’s growing number of cancer survivors, calling their needs a “neglected phase of cancer care.”

The network of cancer specialists also set the first guidelines for penile cancer, a rare cancer whose heterogeneous treatment across North America and elsewhere led to the decision to reemphasize the “gold standard” of care—partial or total penectomy, with wide negative surgical margins—for all but low-grade tumors and very early disease.

NCCN issued the new guidelines at its 18th annual conference on Advancing the Standard of Cancer Care March 13–17 in Hollywood, Fla.

The survivorship guidelines are meant to serve as a resource for “the vast and persistent impact” of cancer diagnosis and treatment on all adult cancer survivors, no matter which type of cancer, said Jennifer Ligibel, M.D., an oncologist at Dana-Farber/Brigham and Women’s Cancer Center and an assistant professor in the Department of Medicine at Harvard Medical School. “A lot of data suggest that lifestyle factors are not being addressed,” she said, such as the need for regular exercise; counseling about diet and nutrition; or memory loss, pain, and sexual dysfunction resulting from cancer treatments.

And yet the number of cancer survivors over the past 35 years has increased exponentially, climbing from 2.5 million in 1975 to an estimated 12 million–14 million in 2012, according to Ligibel. Some 20% of survivors are older than 80 years, whereas 23% are aged 75–79 years. Nearly one-third were diagnosed within the past 5 years.

In defining the cancer survivor, NCCN endorsed the definition of the National Cancer Institute, which considers someone a survivor “from the time of diagnosis through the rest of his or her life.” The definition also includes people touched by a cancer diagnosis: family, friends and caregivers.

Over the past 6 months, the 27-member panel looked at eight distinct areas of concern for survivors, including four never addressed: exercise, cognitive function, sexual function, and immunizations and infections. The panel’s recommendations included the following:

- Cancer survivors, who are now disease-free, should engage in at least 150 minutes of moderate, or 75 minutes of vigorous, exercise weekly, according to observational studies that link regular exercise to better outcomes, especially for breast, prostate, and colorectal cancers. At least 10 large studies looked at exercise and women with early breast cancer, Ligibel said, including the Nurses’ Health Study, which found that women who exercised more than 3 hours per week had 50% fewer cancer recurrences.

- Physicians need to regularly assess survivors’ prior and current physical activity. At least one-third of cancer survivors fall into low-activity groups, Ligibel said, and although comorbidities, such as arthritis or active infections, may be the reason, these need to be addressed.

- Neuropsychological evaluations to determine cognitive function are needed, because data suggest that as many as three-fourths of all cancer survivors experience memory problems. Initial studies show an association with chemotherapy, Ligibel said, but many cancer survivors show problems with memory and processing before undergoing these treatments.

- Providers need to examine how cancer therapy affects sexual function, which is under-reported, according to Crystal Denlinger, M.D., the survivorship panel chair and a medical oncologist at Fox Chase Cancer Center in Philadelphia. At least 90% of prostate cancer patients and half of patients with breast cancer and other gynecologic cancers, for example, experience difficulties, she said, “yet few receive counseling, even though there are treatments out there.”

- All survivors should be considered for appropriate vaccines. “We recommend vaccinating patients at least 3 weeks prior to initiation of cancer treatment, if possible,” Denlinger said. In addition to annual flu shots and pneumonia vaccines, the panel recommended a single dose of zoster vaccine for cancer or transplant survivors aged 50 years or older, as well, unless patients have lymphoma or other malignant neoplasms.

Both Denlinger and Ligibel stressed that implementing the guidelines will require input from primary-care physicians and defining “shared care” with oncologists for managing these late-term effects of cancer therapy. Other challenges that lie ahead, they said, include developing standards for assessing these effects and determining whether survivorship care should be part of separate clinics or embedded in regular clinic visits.
Bartering for Time: Realism Versus Hope

By Susan Jenks

In her new book, The Cost of Hope: A Memoir, Amanda Bennett says that the cost of her husband’s 7-year battle against a rare form of kidney cancer was $618,616—an expense incurred mostly during the last 2 years of his life.

But beneath those figures lies a far more personal story of navigating a complex health care system that tends to compartmentalize care (“We had a doctor for everything,” she says) and a disease that often defies certainty, even in diagnosis.

Bennett, a Pulitzer Prize–winning journalist and former editor of the Philadelphia Inquirer, delivered the keynote address at a roundtable discussion of the emotional and financial impact of cancer at the National Comprehensive Cancer Center Network’s 18th annual conference, March 13–17, in Hollywood, Fla. Today, she is an executive editor at Bloomberg News, directing special projects and investigations.

“The book isn’t even a story about the wicked insurance companies,” Bennett told the audience, noting that she and her husband had good insurance throughout their ordeal. “This is the story about the best of the system, where every person dying seems like a failure. Denial isn’t a strong enough word for what we went through.”

Bennett’s husband, Terence Foley—a “quirky and eccentric man” with a love of bow ties, Chinese history, and jazz, who earned a Ph.D. in his early sixties—learned he had kidney cancer in November 2000. Although doctors initially told him he had collecting-duct cancer, a rare and aggressive disease, he later received a surprisingly different diagnosis from a kidney cancer expert at the Cleveland Clinic: papillary cancer, also rare, but the most indolent form of the disease.

Ronald Bukowski, M.D., a former deputy director of the Taussig Cancer Center, who made that diagnosis and served on the National Comprehensive Cancer Center Network panel, advised Foley and Bennett to do nothing, which they did for more than 3 years, until the cancer’s final return.

The cost of “doing nothing” came to $36,000, Bennett said, after investigating the blizzard of envelopes from various insurers after Foley’s death at the age of 67. The charge came from eight clinic visits for computed tomography scans, which turned out to be a small fraction of the 76 scans Foley had at various institutions during his long illness, as the couple moved around the country for Bennett’s increasingly high-profile jobs. Whereas some providers charged $800, Bennett said, others charged as much as $2,400 for an identical scan.

“Were all of them useful and ordered for a good reason?” Bennett asked. “I’m just as sure not.”

The panel evaluating these and other issues included several other physicians, besides Bukowski, who took part in Foley’s medical care. Veteran ABC journalist Sam Donaldson moderated.

Even now, the doctors said they remain uncertain over the type of kidney cancer that took Foley’s life.

“The tools to make a definitive diagnosis in this illness are still lacking,” Bukowski said. “I said, ‘Do nothing,’ because I felt it was a slow-moving cancer. Some patients may not need treatment even though they have metastatic disease.

Craig Turner, M.D., the Portland, Ore., urologist who removed Foley’s diseased kidney shortly after the diagnosis, agreed. “That’s the uncertainty,” Turner said, explaining the unclear pathology. “We try to speak to our patients with certainty. We’re uncomfortable with uncertainty.”

Keith Flaherty, M.D., director of developmental therapeutics at Massachusetts General Hospital’s Cancer Center and the last physician to treat Foley before his death, described the process as a “question of realism versus hope.” Each medical step