Facing the challenges of cancer treatment as a young adult

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Survival rates for young adults (aged 15-39 years) affected by cancer stand in sharp contrast to the increasing survival rates of both older and younger patient populations; they have not increased since 1975. The reasons for this leveling off are not fully understood, but significant data suggest that this population's low rates of participation in clinical trials have slowed treatment advances, as doctors are learning that cancer in young adults may have different features than cancer in children and older adults. Currently, only about 2% of patients aged 20 to 39 years are treated in clinical trials, compared with more than 60% of children younger than 15 years—a patient population that has experienced an increase in survival of more than 60% since the 1950s.[1]

These troubling statistics have led the National Cancer Institute (NCI) to dub the young adult population the "lost generation," and illustrate the need for more collaborative and communicative approaches to treating young adults affected by cancer. CancerCare client Jackie (who received a diagnosis of thyroid cancer while attending college in New York City) did not receive any information or encouragement from her doctors and nurses about participating in clinical trials. "Looking back, I really wish this option had been presented to me," she says. "I would've been first in line to sign up."

Jackie, like many young adults affected by cancer, had to self-advocate in lieu of having family members help coordinate her care. "I'm from California and going to school in New York, so my family really can't get out here that often," she says. "I have to take the reins on my treatment." Young adults with cancer may suddenly be required to make medical appointments, receive test results, and gather cancer and treatment information. One way to help your patients avoid feeling overwhelmed is to stress the importance of keeping thorough records, with separate files for medical records, test results, bills, etc. A binder or accordion folder can be useful for keeping all of these materials together.

A young adult's expertise in navigating health care resources and policies should not be overestimated. This obstacle was a major one for Jackie. "I was covered under my college's health insurance plan," she explains, "but nobody in the student health center could help me with navigation. I was being treated in multiple hospitals—I just felt so overwhelmed and confused." The health care professional should open up this dialogue with the patient to gauge how much patient navigation may be required, and then refer him or her to the appropriate navigational resource.

Another important consideration is young adults' lifestyle and daily activities, as these

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may influence treatment recommendations. Discuss how a treatment timeline may affect their ability to work or attend school, with the caveat that scheduling changes may not always be possible. An example of this would be to propose delaying a round of chemotherapy so that a young adult can attend a social event that is important to them.

The costs associated with treatment are a major challenge for patients of all ages facing a cancer diagnosis. Young adults' finances in particular can be strongly affected by the costs of cancer treatment, as many are in school and not working, unable to work, working part-time, or employed in an entry-level job. Organizations like Cancer*Care* (1-800-813-HOPE [4673]; www.cancercare.org) provide much-needed financial help. Cancer*Care* also provides referrals to young adult-specific resources. The Cancer*Care* Co-Payment Assistance Foundation (1-866-55-COPAY [866-552-6729]; www.cancercarecopay.org) provides up to $10,000 per year in co-payment assistance to eligible people. Additionally, the I'm Too Young for This! Cancer Foundation (www.i2y.org) has a resource listing of financial assistance grants and scholarships for young adults.

The number of young adult-specific support groups and resources has, fortunately, increased in recent years. Jackie found the support she needed through a young adults survivor support group at Cancer*Care*. "For the first time [since my diagnosis] I felt very connected," she says. "I found a network I didn't have before."

Encourage your patients to consider sharing their experiences through support groups (online or face-to-face), as this can help young adults feel less alone and give them the opportunity to compare their experiences and solutions with other young adults. Cancer*Care* offers both online and face-to-face support groups. More support groups for young adults can be found through LiveSTRONG (www.livestrong.org), the I'm Too Young for This! Cancer Foundation, and Planet Cancer (www.planetcancer.org). ■

Helen Miller is CEO of Cancer*Care*.

REFERENCE

1. Treatment and clinical trials. National Cancer Institute Web site. http://www.cancer.gov/cancertopics/aya/treatment. Accessed May 16, 2011.