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Expert Q&A: What Comes Next After Finishing Treatment [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 05/2014

Listen to theCancer.Net Podcast:Finishing Treatment: What Comes Next?, with Lidia Schapira, MD[3].

Watch theCancer.Net Video: Finishing Treatment: What Comes Next, with Lidia Schapira, MD [4], adapted from this content.

As people complete their cancer treatment, they may experience a range of emotions, from relief that treatment is over to apprehension about the future. In some ways, this transition is one of the least understood aspects of the cancer experience. Here, Cancer.Net talks with Lidia Schapira, MD, about coping with the end of active cancer treatment.

Q: What are some immediate medical concerns of patients once they've finished active treatment?

A: Typically, there is a surge in anxiety and worry over the possibility that the cancer will return once active treatment is completed. Often, people feel they are not doing enough to actively fight the cancer. Another common problem is that some physical and psychological changes don't disappear with the last treatment and seem to last for months or years after treatment ends. A few examples of such symptoms are fatigue, lack of stamina, difficulty focusing, changes in skin texture, or neuropathic (nerve) changes in fingers and toes. People often want to know what signs to look for to detect a cancer recurrence (return) as early as possible and to recognize the long-term side effects of treatment [5]. For example, a person who received a medication that may affect his or her bone density needs to know how his or her bones will be monitored and what treatments are available.

Q: What are some initial psychological concerns of patients once they stop active treatment?

A: These include worries about cancer recurrence, one's identity and future, and dying young or leaving things undone. Some patients may also suffer from poor body image or low self-esteem because of the treatments they received; they often need help to learn to accept their new body.

Q: What are some ways of coping with these concerns?

A: We know that worrying alone feels awful and makes the sense of distress experienced by many patients and survivors worse. Being able to understand one's fears and to talk about them is a good starting point for effective coping. Ultimately, a patient's inner strength and resilience allows him or her to endure this experience, sort through available options, and define a path or journey through the difficulties that lie ahead. Effective coping requires the ability to understand the situation, think through alternatives, ask for and experience the support of others, and feel comfortable with the chosen course of action or treatment.

Q: What about the effect of cancer on a person?s family, friends, and caregivers?

A: Cancer affects not just the individual undergoing treatment, but the entire family unit. Spouses, children, parents, and friends often suffer along with the patient and may need information about the transition to survivorship and assistance coping with their emotions.

Q: What should patients and doctors discuss during the last few appointments?

A: The last few appointments should allow patients time to discuss any concerns they have about the future, clarify the treatment given, and revisit the prognosis, which is the chance of recovery. They should also provide them with the necessary tools to advocate for good care going forward and coordinate this care with the primary care doctor. Every patient needs to understand his or her diagnosis, the treatments received, possible late complications or side effects of such treatments, the follow-up care schedule proposed, and who will be involved in his or her ongoing care.

Q: How else can survivors prepare for life after treatment?

A: Survivors should ask their oncologist for an "end of treatment summary" that outlines the original diagnosis, including the cancer type, stage, and the treatments received. It should also clearly state the proposed schedule for follow-up visits and recommended testing to monitor the person's recovery.

Another, very helpful resource is a support group [6]. It allows survivors to share experiences and give and receive advice and support from individuals who are outside their circle of family or friends.

Meanwhile, some may find it useful to look for more information regarding their specific cancer type or information on coping with cancer using web-based materials, while others may turn to literature, hobbies, or spiritual advisors to help them move forward. The important message is that life may be forever changed by the experience of having cancer, and those changes deserve careful attention and respect.

Q: Is there anything else you would like to add?

A: I am often impressed by the enormous expressions of gratitude I hear from cancer survivors. So many wish to give something back and are genuinely changed by having received so many kindnesses during their cancer experience. I witness the volunteers at our cancer center, the advocates, and those who write or fund programs or walk for miles to raise money for research. Those positive feelings are often set in motion after the treatment is over and during the transition to survivorship.

On the other hand, we need to recognize that many live with cancer and an uncertain future; this is ever present in the thoughts of many of our patients as they transition from active treatment to survivorship. It's the idea that there is a revolving door, and, at any moment, a scan may land them right back in the territory of active cancer treatment. While that fear is completely normal and appropriate, the unique challenge facing survivors is to get on with living, celebrate the joys of the present, and hopefully to recognize when they need help and ask for it.

Dr. Schapira is a medical oncologist at Massachusetts General Hospital and serves as the Cancer.Net Associate Editor for psychosocial oncology.

Links:
[1] http://www.cancer.net/survivorship/life-after-cancer/expert-qa-what-comes-next-after-finishing-treatment
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/sites/cancer.net/files/Finishing_Treatment_What_Comes_Next.mp3
[4] http://www.cancer.net/node/27371
[5] http://www.cancer.net/survivorship/long-term-side-effects-cancer-treatment
[6] http://www.cancer.net/coping-and-emotions/managing-emotions/finding-support-and-information/support-groups