

End of treatment: laugh or cry?

Susan E. Carter, PhD, MFT | Claremont, CA

Compared with the close monitoring and almost daily contact patients have with physicians and staff, the end of chemotherapy or a course of radiation treatment feels to many patients as though they are being “dropped off a cliff.” They may be glad to be finished with these procedures, but the end of treatment represents a new era of doubt and worry: Will I be all right without the supervision of my doctors and nurses? What if my cancer comes back? How do I get back to normal? Physicians can greatly help—or hinder—patients during this fragile period. A number of comments, both positive and negative, are enumerated, as well as an explanation of patients’ states of mind.

The last chemotherapy or radiation procedure is called the end of treatment. Physicians tell their patients that “we see no evidence of disease” and that they will be followed closely for the next few months or years. But in comparison to the close monitoring and almost daily contact and visits, it “feels like being dropped off a cliff” to patients and their family members. To patients, the busy schedule and the regular support of nurses and physicians have provided a supportive psychological, as well as medical, value.

Physicians and staff encourage and anticipate the celebration of the end of irradiation, chemotherapy, or surgeries. Even though they are glad the procedures are completed, patients report increased feelings of depression and anxiety. Physicians and staff must be aware of these emotions, which may have been evident intermittently throughout treatment, may emerge immediately after treatment or may even appear 6 to 9 months after active treatment ends. Frequent comments include: “I felt so strong then, and now I feel weak and vulnerable” or “I was so busy with the rigors of treatment that I didn’t have time to think about what was really happening to me—now what?”

Confronting the emotions, the changes, and the lifelong concerns resulting from cancer may be delayed due to busy appointment schedules; difficulty coping with side effects; and the near-constant support of the medical team, staff, and friends, as well as the denial technique of focusing on the tiny details to avoid the looming and frightening larger threat. When these distractions disappear, patients are left to wage a private inner battle with their doubts, fears, and life changes.

They may wonder if their feelings of depression, anxiety, fear, and sadness are normal and if their worries, uncertainties, and fears are valid (Ta-

ble 1). It is important to reassure them that these emotions are normal, saying, “You will be fine!” is usually not very helpful. During this recovery after active treatments, the scary questions begin to surface: “What if my cancer comes back?” This question expresses both the fear of recurrence and self-doubts about being able to handle it. No amount of reassurance from others seems to allay this concern because this is about inner self-doubt. When asked exactly what they *would do* if it came back, most patients say they would undergo treatment and fight again. Once that question is answered, *by them*, they may be able to put their worries away, because they know what to do.

Reassuring patients

High levels of anxiety and worry about unknown factors are common at the beginning and end of treatment. It is important to acknowledge these emotions as normal and valid and to reassure patients that they are not “going crazy.” The expression of anxiety can range from simple complaints of anxious worry and intrusive negative thoughts to sleeplessness, panic attacks, and thoughts of suicide. At the lowest levels, worry is often a result of good questions, asked over and over but never answered, which then begin to spiral down into the obsessive repetition of the same or similar questions, creating anxiety and even panic. Patients may reduce anxiety and develop self-confidence when they slow down the inquisition and identify and answer questions such as: “What if...?” “Who would I turn to if...?” “Why?” or “What if I become a burden again?”

Manuscript received July 28, 2004; accepted July 31, 2004.

Correspondence to: Susan E. Carter, PhD, MFT, 428 West Harrison Avenue, Suite 101A, Claremont, CA; telephone: (909) 621-2819; e-mail: scarcer00@earthlink.net

Commun Oncol 2004;1:179-181 © 2004 Elsevier Inc. All rights reserved.

TABLE 1**End-of-treatment feelings and experiences**

- Isolation and abandonment
- Worry, anxiety, and panic
- Loss of support
- Self-doubt and poor self-image
- Coping with side effects of treatment (both temporary and permanent)
- Depression (mild to suicidal)
- Grief and sadness due to losses
- Uncertainty and doubt about future
- Helplessness and hopelessness (loss of power)
- Fear of recurrence
- Lack of memory and concentration ("Have I lost my mind?")
- Residual fatigue for up to a year
- Anger
- Family and social issues
- Workplace issues
- Financial and insurance challenges
- Search for the new definition of "normal"
- Difficulty making long-term plans
- Fear of the power and truth of statistics
- Changes to body, self, and sexual images and function

Panic and anxiety attacks, the sudden onset of acute worry and stress, require immediate action. Both medications and behavioral changes are needed to alleviate these high distress levels. A simple three-step behavioral technique can help reduce anxiety and panic. First, the patient is asked to breathe *out* slowly (they will automatically breathe in—it is human physiology). Slow and deep breathing can reduce the tension and reassert a more regular breathing pattern. The second step is reassurance, both from others and self. "Oh... I know what this is and what to do about it" can be very comforting. It is the "uh oh" that can alarm and escalate the panic and anxiety. The third step is to have a "pill in your pocket." Many people carry anxiety medications around with them and never actually take them. It just reassures them to know that they can. Early recognition and identifica-

tion of anxiety, reassurance from others or self, and the use of relaxation and breathing techniques can help to diffuse an escalating situation.

Depression is often reported during this phase. The life the patient has fought for suddenly becomes a dark burden of tears, doubt, inertia, and sadness. These feelings evoke a sense of vulnerability, insecurity, and weakness. Even the cheeriest, healthiest patient can experience depression and anxiety. These moods are common at various times throughout the cancer experience, but when they persist, permeating a patient's life, they must be addressed and treated.

These "blue moods" may be chemical imbalances resulting from side effects of medications and treatments, or they may be a recurrence of pre-existing depressive tendencies. Whatever the source of depression, it may need to be treated with antidepressants or other psychopharmacologic agents. High levels of depression can be life-threatening and can prevent a good quality of life after cancer. Referrals to counselors, support groups, chaplains, or psychiatrists may help reduce depression to an "acceptable" level.

List of 'grief-ances'

Although some feelings may appear to be depression, they may actually be grief and sadness due to losses resulting from a cancer diagnosis. Those who are depressed often report an absence of emotions or "numbness," whereas grief will be described as profound sadness or anger—in other words, high levels of emotion. A question such as "Do you feel sad?" often elicits a different response from a grieving patient than from a depressed patient. Grief may elicit tears and anger, whereas depression may present as confusion and impassiveness. It is important to periodically assess all levels of grief and depression, as they are treated differently.

The losses that patients incur may be large or small, temporary or permanent, conscious or hidden. They

may be more focused on the temporary loss of their hair or the permanent loss of their lives than the cancer itself. Patients are often very angry about these losses. It may be only after treatment ends that they realize how much cancer has disrupted and affected their lives, forever. They will need to face and grieve these losses before they can move on to see the positive aspects of what they have left. Ask patients to identify what they are missing and what they have lost when they feel the sadness and tears, maybe even writing down a list of "grief-ances." As with many things, when you name them, you can master them.

The grief recovery process begins with only being able to see the dark and painful losses; then it progresses to a time of experiencing both loss and positive thinking; and finally, the majority of experience is spent embracing a positive outlook on life with an occasional reminder of the painful loss. This can be a painful, yet successful process, and many patients and medical personnel try to skip the painful confrontation of loss and try to move on too quickly (Table 2).

Looking ahead

Many patients have questions about coping, such as: "What do I call myself. Am I a survivor yet?" or "How do I get back to normal?" These are questions about changes in perception and perspective. Whatever patients choose to call themselves, they need to be encouraged not to define themselves in terms of their cancer; they had cancer, it did not have them. A "victim" speaks as if his cancer defines him ("I am a cancer patient"). A "survivor" centers his life around his recovery from cancer, and a "thrifer" focuses on her life ahead with occasional

ABOUT THE AUTHOR

Susan E. Carter, PhD, MFT, is a licensed marriage and family therapist in private practice in Claremont, CA. She specializes in psycho-oncology.

TABLE 2**Helpful comments from physicians and nurses**

- "We are not abandoning you; we are changing the focus and frequency of your visits."
- "Tell me what your concerns are."
- "I know someone who can give you the tools and techniques for coping with these emotions and feelings."
- "I hear these concerns often at the end of treatment; they are normal and important to deal with."
- "We want you to live a good quality life; I will refer you to someone who can help you...."
- "I am asking you to consider some medications that might help" or "I can refer you to someone who specializes in emotional and psychological well-being for cancer patients who might be able to help."
- "You will be 'normal,' but it will be a 'new normal' that encompasses all the things that have happened to you since diagnosis."

Dismissive and ineffective comments

- "You'll be fine."
- "It is normal—get over it."
- "Look on the bright side."
- "How could you feel this way after we fought so hard for your life."
- "Just get back to work; you will feel better."

references to her illness. These differing outlooks may dictate how people cope with the rest of their lives.

Too many things have changed to go back to normal; "back there" was the cancer. Their physical and emotional lives have changed dramatically: priorities, outlook, bodies, relationships, self-image, and bodily functions. Their "new normal" must incorporate what they have learned and how they have changed.

The uncertainty of life has crashed in on these patients. Previously seeking to control all aspects of their lives by finding clear and precise answers, they now have to learn to prefer vague uncertainties: "We don't know for sure" or "Let's try this." When a doctor says, "We can't find anything," that is now considered good news.

Is it over? Probably not. There will be reminders: side effects, more tests and appointments, continuing changes in priorities and outlook. This is a time of emotional and physical adjustment, as well as recovery. Just as a referral to a specialist may resolve extreme physical discomfort, so too can a referral to a mental health professional, who is trained to assist in coping with cancer

issues and in helping to resolve physical suffering. Patients can safely and honestly tell things to a trained professional that they might not be able to discuss with friends and family. The basic question for patients, as well as for all of us, is, "How are you going to live the rest of your life, however long it is?"

Perhaps we need to use a different phrase instead of the "end of treatment." Changing the focus of treatment is not the end of anything. Treatment is not actually completed after the last chemotherapy or radiation treatment, it just changes. Perhaps patients would feel less abandoned and isolated if "the end of treatment" were presented as a change in the focus and frequency of treatment, a still-vigilant and continued follow-up on their progress after cancer.

The ultimate question for patients finishing active treatment is the same as the question for all of us: "How are you going to choose to live the rest of your life, however long it is?"

Do you have any stories to share about helping patients deal with the end of treatment? We want to hear from you. Please e-mail your comments to Randi Gould, Managing Editor, randi.gould@biolc.com.