

The Waiting Process

Hurry Up and Wait!

Ernest H. Rosenbaum, M.D.

Isadora R. Rosenbaum, M.A.

Susan Diamond, L.C.S.W.

David Spiegel, M.D.

Andrew W. Kneier, Ph.D.

“The doomsday scenarios you conjure up during stressful waiting periods are usually far worse than reality.”

Waiting for appointments and test results can turn living with cancer into a full-time occupation and preoccupation. You count the weeks and days until your next appointment and make note of every ache and pain, thinking it might be a signal that your disease is worsening. On the day of your appointment, you are so anxious that you arrive early at your physician's office, only to discover that he is behind schedule, increasing your waiting time as well as your apprehension. During your visit, your physician orders the required tests and tells you to go home and wait for a phone call—or suggests that you call back in a few days or a week to get your test results.

You are always waiting for something: the initial diagnosis following surgery; a biopsy, mammogram, or fine needle aspiration; the results of treatment; and when in remission, your next checkup. The most difficult aspect of waiting is the open-ended uncertainty of not knowing what is happening inside your body. Conversely, “knowing” can be a relief—even when the news is not good—because you and your physician then can take action and discuss therapeutic alternatives.

You should also be aware that the time you spend waiting for appointments and for information on your medical status is often determined by circumstances beyond your control or that of your physician. For example, because of economic pressures, most physicians see more people per hour today than they saw in the past, resulting in shorter office visits. This can make you feel that you have received insufficient consideration of your psychosocial needs. Physicians' increasingly heavy workloads also lead to longer waiting periods for an appointment, whether for an initial consultation or for subsequent therapy.

The operating procedures of insurance companies and Health Maintenance Organizations (HMOs) can also lead to delays that, in turn, increase your apprehension. These organizations generally require that physicians obtain an authorization from them before ordering certain types of tests, therapies, and surgical procedures. You or your primary physician must also request permission from the insurance company or HMO to

consult with a specialist and you must, of course, choose one who belongs to your plan. If you choose a specialist who is not on your plan, you may find that the plan will not pay (or will pay less) for the services. Any or all of these negotiations can mean added hours or days of fretfulness for you.

In short, facing delays is a part of the treatment of cancer, but with a little mutual understanding and effort, you and your physician can attempt to lessen those that are occasioned

by heavy patient loads, complex diagnostic tests, and insurance company and HMO requirements. Hopefully, in the last instance, future legislative action will streamline some of the medical management procedures that currently prolong certain waiting periods and exacerbate what is already a highly stressful time in anyone's life.

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Reducing Stress in the Stressed-Out World of Cancer

Susan Diamond, L.C.S.W.
Ernest Rosenbaum, M.D.
David Spiegel, M.D.

Coping with cancer entails navigating effectively between being so overwhelmed by threat that you feel helpless and denial that the threat exists. Getting that balance is a constantly shifting and demanding process. It involves accepting temporary crisis situations and utilizing the disruption to formulate new plans of action.

The pattern of response you establish during an acute crisis is likely to become cemented in place, regardless of its relative effectiveness. *Effective* coping involves taking in and processing the emotional reaction to the danger and seeking the opportunity for a response that at least mitigates the danger.

Acknowledge the problem: It is better to face head-on whatever is threatening you than to try to deny or avoid it.

Be specific: See the problem as being on a continuum, more or less difficult, rather than as an all-or-nothing catastrophe.

Seek information: The more you know about a problem, the more likely you are to figure out a better way of dealing with it.

Feel what you feel: Difficult situations bring strong emotions with them. Let them come and learn from them. Emotions can point out to us what is important and, when shared appropriately, can build intimacy and support.

Seek social support: Don't do it alone. Family and friends often feel more helpless than you do. They welcome any opportunity to help. Give them many.

Find an Active Response

You will feel better about any problem when you can find a way to be active about it. Even if you can't solve the problem or make it go away, you will feel better if you can do something about some aspect of it.

False Positives

Don't force yourself to be more upbeat than you feel. Indeed, defining what constitutes a truly positive attitude is a complex problem. Being too positive all the time can verge on denial. This can inhibit obtaining

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necessary medical information and treatment. It also can lead family and friends to actively discourage the expression of appropriate sadness and fear.

One of our patients related to her support group that when she started to cry in front of her husband about the progression of her inflammatory breast cancer, he said: "Don't cry, you'll make the cancer spread." Another member of the support group referred to this as the *prison of positive thinking*. We see many people with cancer whose family members are afraid that giving vent to these negative feelings will somehow unleash the cancer itself, as though the feeling uncontrolled is the same as the disease uncontrolled. Many people are desperate to do anything they can to control the illness, and are willing to exist in an emotional straightjacket if it will somehow improve their odds of survival. Yet another downside of the positive attitude often recommended to someone with cancer is that progress of the cancer provides fertile ground for inappropriate guilt: "If I can control the spread of disease through my attitude, and the disease has progressed, then there must be something wrong with my attitude." There is simply no medical evidence that a positive attitude *per se* has any effect on the course of cancer.

Group Support

Harboring fears and anxiety about cancer can be absolutely paralytic. The opportunity to share thoughts and concerns and express even the most frightening feelings, such as "I'm terrified I'm going to die," offers enormous comfort, allows you to realize you are reacting normally to an abnormal situation, and helps you regain your emotional balance while significantly reducing your stress (Spiegel, 1993).

Sharing experiences with other people who have cancer is a potent experience. Many people find that being a member of a cancer support group offers multiple benefits. The very thing that has made you feel separated from the rest of the world is your admission ticket into the group. Thoughts and feelings that previously seemed bizarre are normalized. It is the rule rather than the exception to feel terrified, enraged, grief-stricken, immobilized, and wondering if you're going to die. You can experience tremendous relief in finding out that you are not alone and that others sharing your dilemma accept you and understand.

Just as the group helps you integrate a new sense of self, it simultaneously helps you define and revise what is important to you. The issue of how to make the best use of time becomes paramount in the face of an uncertain future. This usually involves seizing the moment and taking full advantage of the present instead of becoming exclusively focused on the future. You may begin rearranging your priorities as you develop new interests, or expand on or drop old ones. Cultivating experiences that are enriching and pleasurable should become a key goal; eliminating those that no longer interest you is another.

For example, a woman with progressive, metastatic breast cancer decided to undergo a bone-marrow transplant as a "last ditch" treatment. Not knowing what the outcome of this procedure would be, she determined that there were certain things she wanted to accomplish in the event she died. She and her partner took a long-delayed vacation to Hawaii where they agreed to make a more formal commitment to their relationship prior to her hospitalization.

Another woman, a prolific poet with incurable brain cancer, was encouraged by

her partner to take up painting. She did and, to her delight, found herself immersed with an almost child-like fascination in a new world of shapes and colors (some of her paintings were exhibited at the hospital where she was treated). Rather than giving in to her cancer, she viewed it as an opportunity for creative growth and unanticipated pleasure.

Some people with cancer continually reorder their priorities. A lovely woman of forty-one with advanced ovarian cancer chose to forgo a level of pain medication that, essentially, would have left her pain-free but unconscious. She wanted to stay alert, aware, and connected to the people she loved. For her, the importance of this far outweighed being physically comfortable.

Clearly, openness and expressiveness—emotionally and in other areas—is critical to your overall recovery and goes a long way toward helping you manage the inevitable stresses of the disease. Using family and friends as a resource is a crucial part of this process. Early involvement of your family in both decision making and treatment helps you integrate your experiences with cancer into the rest of your life. Family and friends can encourage you to talk about how you feel and about what is happening to you. A simple statement from someone close, such as “I’m scared too, but we’ll fight this together” is both encouraging and comforting. The relief in knowing that you can give voice to what is frightening and painful can remind you that you’re not fighting this battle alone.

As barriers to communication are overcome, you can benefit from and help your

natural support system while feeling sustained through the cancer experience. In sharing all emotions, both the positive and the negative, you don’t hide or deny any aspect of your experience. It also offers those who care about you a way of better understanding your experience, as well as the means to feel closer to one another and to you.

Some people diagnosed with cancer find that they need the privacy of individual counseling or therapy to work through some of their feelings about their cancer. A therapy session with a specially trained and caring professional at the time of diagnosis or recurrence, with the potential for continued visits, provides a safe place for you to discuss your feelings about and experience with the cancer. This can help lessen fear and offers a setting for the diagnosis and treatment of more serious forms of anxiety and depression.

Serious sleep and appetite disturbance or persistent suicidal thoughts call for professional evaluation. Although the thought of living with cancer will never be free of anxiety, you may need help in recognizing that while cancer is now an undeniable part of your life, it is not the only part.

Your renewed ability to see yourself as an active participant in your life will help you maintain your emotional perspective, which will help keep the stresses of living with cancer from constantly intruding into your life.

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When Your Spouse Has Cancer

Andrew W. Kneier, Ph.D.

What you can and should do when your partner contracts cancer depends on your partner's personal needs. Each situation is different. Your partner may be newly diagnosed, dealing with metastatic cancer, or living in a kind of limbo, not knowing whether the cancer has regressed. Here are some general guidelines that could help you provide the kind of support your partner needs:

Face Cancer Together

Although your spouse has cancer, the illness is really happening to both of you. Your life is being disrupted in many of the same ways. You are sharing many of the same emotions and concerns. You are both challenged to find constructive ways of dealing with the disruptions and threats posed by cancer and with the side effects of medical treatments. It can be tremendously reassuring and comforting to your loved one to know that the two of you are facing the illness together and that your support and involvement will be steadfast and unwavering regardless of what happens.

Here are some of the specific issues that you should try to face together:

- How serious is the cancer?
- What is the best treatment, and what are the pros and cons of different options?
- Are there clinical trials to consider, or perhaps complementary or holistic approaches?
- What roles or division of labor should we take in learning about these matters?
- What should we tell our children, and how can we best help them in dealing with this frightening situation?

- What changes do we need to make in our daily routine to accommodate the need for treatments and to deal with side effects?
- What does our family need in the way of support and practical help from relatives, friends, and our religious community?
- How can we best reach out for the support we need?

Discussion Is Better than Assumption

Do not assume that you know what your spouse is thinking or feeling about the cancer, or that you know what he or she needs from you. You might think your spouse is mostly scared, when actually he or she feels more sad or perhaps guilty about the consequences of the cancer for you. You might think that your spouse is strong and resilient, when actually he or she feels vulnerable and dependent on you, but may not want to let you know that. You might think that your loved one wants you to offer encouragement and hope, when actually he or she just wants you to say "I'm with you in what you are feeling, and we'll face this together no matter what happens."

The point is to talk with your spouse about his or her emotional reactions and concerns and to ask what your spouse needs from you. Some of these needs may be concrete or practical: going together to doctor's appointments, becoming educated about his or her cancer and the treatment options, handling all the phone calls from friends and relatives, and taking over more household chores. Other needs may be

more emotional: being attuned and responsive to what your spouse is feeling, encouraging your spouse to confide in you, and offering empathy and support during difficult times.

Support Your Partner's True Feelings

Most cancer patients feel pressure to maintain a positive mental attitude, and too often this pressure prevents them from expressing their true feelings. Your partner might hold back in sharing legitimate fears because he or she does not want to disappoint or burden you, or because he or she thinks that negative emotions might jeopardize healing. Actually, it is the suppression of fears, sorrow, or anger that could jeopardize your partner's psychological adjustment and immune response. Your loved one probably has good reasons to be worried and upset, as well as to feel hopeful and optimistic. You should try to support and validate both sets of emotions (not only the positive ones).

Confront Sexual Issues

Your spouse's cancer and the treatments have probably affected his or her sexual interest, sexual functioning, or feelings of attractiveness. Some common examples are the loss of libido caused by chemotherapy and hormonal therapy, the impotence

caused by prostate cancer treatments, and the body image effects of mastectomy and reconstructive surgery. Even without such specific problems, the depression that cancer can cause can reduce libido and sexual functioning. The bodily or mood changes in your spouse can also cause you to lose interest.

The key to dealing with these issues is open communication. Because your partner might be reluctant to broach these topics, you could take the lead by acknowledging these issues and conveying your desire to face them together. You might also go out of your way to reassure your spouse of your love and devotion and that your feelings are not motivated just by physical attractiveness or sexual performance, that your main priority is his or her survival, and that you continue to desire an intimate physical relationship.

I know of hundreds of couples who have followed these principles. They have told me that the bond between them has actually been deepened and strengthened. "It's ironic," one husband told me, "but somehow having to face death, and having to say good-bye to each other if that happens, has made us hold on tighter and cherish what we have."

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