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Cancer Perspectives

—A clinician and a researcher give their personal views.



William C. Dooley, M.D., and Theodore L. DeWeese, M.D.

Although all doctors have the same goal of trying to “cure” or eliminate cancer, clinicians and researchers often approach the problem from different angles.

Clinicians, who treat patients already diagnosed with cancer, are battling in the trenches. Every day, they help patients make life-or-death decisions about their care, and they see the happy successes and painful setbacks up-close. For them, “cancer” is reflected in the patients they treat. “Cancer” is a thousand different faces, each with a name, each with a special story to tell.

Researchers are no less affected by cancer’s “personal” toll, but their goals are wider. Instead of focusing on a cure for a single patient, researchers

strive to find answers that will allow them to cure all cancer. They spend their lives in laboratories, agonizing over discrete problems, such as cancer cell metabolism or hormonal influences on prostate cancer proliferation. If they find a promising solution to a problem, they test it, retest it and retest it again...first in a petri dish, then with animals, and finally with people. Each experiment provides another crucial piece of the puzzle that will ultimately lead to a cure.

Because of their different approaches to cancer, clinicians and researchers maintain perspectives that vary in subtle ways. Drs. William C. Dooley (a clinician) and Theodore L. DeWeese (a researcher) compared notes on a number of different topics:

What's the best way for patients to understand what's happening to them?

Dr. Dooley: I frequently tell patients that finding an invasive cancer is like finding a dandelion gone to seed in the middle of a

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A Survivor's Story



Celeste Carr

Celeste Carr was diagnosed with cancer twice in 2 years. The experience has benefited many lives...including her own.

On Friday, August 8, 1997, Celeste Carr went for her very first mammogram, because she had found a lump in her left breast. “I wasn’t worried,” she recalls. “Both my sisters, like my mother, were prone to benign cysts. I figured mine was also

a harmless cyst.”

But the doctors suspected otherwise and performed a needle biopsy at the same appointment. On Monday, three days later, their suspicion was confirmed with the formal diagnosis – invasive ductal carcinoma, which

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Coming to Grips with Cancer



by

Carole F. Seddon, LCSW

— Patients deal with shock, fear, in wake of diagnosis.


Coming to grips with a cancer diagnosis isn't easy. At first there is shock, fear and, for many patients, an overwhelming feeling that life has spun out of control. Next comes treatment – surgery, chemotherapy, radiation – that can leave you feeling exhausted and debilitated. But for many patients treatment is also empowering. Unpleasant as it can be, once treatment begins some of the unknown is lessened. Many find treatment to not be as terrible as they expected and they begin to feel some sense of safety working with the medical staff they respect and trust. Patients often also feel better emotionally because they have a sense that they're fighting back against the cancer.

Once treatment is over, it is normal to experience some very confusing emotions. There is the relief that many expected, but it many times is coupled with anxiety, depression or tearfulness again. This is usually a surprise to cancer patients and family members. For some this occurs because they kept their feelings stuffed during treatment. For others it is simply the fact of fewer visits with an oncologist, a radiologist, or a surgeon that leaves them feeling scared again. For most there is the realization that this will not just all go away as return visits are scheduled to check for any cancer. They find themselves grieving for the loss of life as it was, free of the fear of cancer.

One way to handle these anxieties and fears is to try to focus on the positive things you have been told about your cancer and the treatments, not just the fears that run through your head. That's not to say that feelings of sadness, fear, anger or anxiety are wrong or that it is wrong to express them. It is very important, for example, to be able to cry when you need to. However, many of the

patients I have met through my 18 years in oncology have told me that they do best when they can focus on the present and try to avoid dwelling on "what if" scenarios. It can also be helpful talking to survivors with your particular type of cancer. After I was diagnosed with breast cancer 7 years ago, I met a woman at my first Survivor's Day who told me she was a 45-year survivor of breast cancer. I think of her whenever I'm frightened that my arthritis or my bronchitis is really a recurrence of cancer. The knowledge that it is possible to survive the disease and outlive it by many years was enormously comforting and made me feel much more optimistic about my chances.

Much of coming to grips with a cancer diagnosis is simply a matter of time. After treatment it is natural to worry that every cold or flu, every minor ailment, is a sign that the cancer is back. Only time and positive experiences will help you rebuild confidence in your health.

It is also important to recognize that positive things can come from this experience. Dealing with serious illness helps many people work out what's most important and meaningful to them and enables them to put the daily "ups and downs" into a better perspective. Beyond that, hope, optimism and a little love from friends and family can help build or rebuild your emotional serenity and permit you to accept the fact that "for today" you are essentially OK. 

Carole F. Seddon, a licensed clinical social worker, is Clinical Coordinator of the Cancer Counseling Center at the Johns Hopkins Oncology Center.

Fighting Cancer Tomorrow



— Expect breakthroughs in preventing and treating cancers in the 21st century because of what we're learning today.

by

Martin D. Abeloff, M.D.
Director, Johns Hopkins Oncology Center

Ever since 1971, when President Nixon signed the National Cancer Act, our ability to understand and treat cancer has been improving continuously. But the most dramatic forward leap has occurred in the past decade, with a revolution in our understanding of molecular and cellular biology.

We now understand a tremendous amount about the biology of cancer, its molecular basis and how cancers develop and progress. Because of this understanding, we are now at the threshold of being able to apply this knowledge clinically – not only to treat cancers, but also to diagnose them earlier and even prevent some forms altogether.

Preventive Drugs

For example, medical scientists have long treated advanced breast cancer patients with a class of drugs called “selective estrogen receptor modulators,” or SERMs. But in the last year, one of these drugs – tamoxifen (*Nolvadex*) – was tested on a large population of women at high risk for developing breast cancer and was found to be effective at preventing the disease.

There are still a lot of unanswered questions about which women should take tamoxifen, and whether it actually prevents breast cancer from starting or whether it eradicates breast cancer that is already present but has gone undetected. But the research taught us a lot, and is leading to more studies on the preventive role of drugs. In fact, in December 1998, the federal government announced it would embark on a major trial to compare tamoxifen and raloxifene (*Evista*) to see which works better in preventing breast cancer.

We're also testing retinoids – drugs that are vitamin A derivatives – in large studies of smokers and others at high risk of developing lung cancer. It

will take several years to determine whether retinoids reduce their risk of developing lung or other cancers. But if they do, retinoids will also be added to our cancer-fighting arsenal.

Immunotherapy

Immunotherapy, which involves enhancing the body's natural immune response to cancer cells, looks very promising as a way of fighting cancer in the future. A pioneering new treatment, herceptin, received FDA approval in September 1998 as the first in a wave of genetically engineered antibody treatments for breast cancer.

Herceptin is a monoclonal antibody, one of a group of drugs that attacks specific cancer cells that produce a protein called Her-2 or Her-2/neu. Now in the earliest stages of development, herceptin has been effective in extending the length and quality of life of patients with advanced breast cancer. Indeed, studies show that when herceptin is administered by itself, it causes disease regression in 15 percent to 20 percent of these patients. When it is combined with chemotherapy its effects are even greater. We're hoping that the drug will contribute to a cure for those women with early stage disease. More herceptin-like therapies are now being developed.

Vaccines are also being developed as part of this immunotherapeutic approach. Our immunologists and clinical researchers here at Hopkins have pioneered the development of vaccines for kidney and pancreatic cancers; vaccines for prostate cancer are also being tested here; and we are also very hopeful about an effective vaccine for cervical cancer.

Chemotherapy


Several new classes of chemotherapy drugs are being introduced, including some to deal with complications of cancer. For instance,

a category called “bisphosphonates” actually prevents, or at least controls, cancers that have spread to the bone. Although they may not treat the cancer directly, they have an effect on bone that is very helpful. So this is a vast area of potential benefit to patients.

Scientists are very excited about our increasing ability to screen large numbers of drugs to determine if they can correct, or at least interfere with, genetic abnormalities. Using computerized technology, we now can quickly identify molecular abnormalities in cancer cells and then just as quickly screen various drugs in vitro to see which ones are effective against these abnormalities. We're now in the pre-clinical phase with this technology, but once this information has been analyzed, the drugs will be ready for clinical testing in people.

Screening Tests

Also in the future, you can expect to see a viable screening test for certain cancers, such as lung cancer, that will allow us to detect the disease at its earliest stages – when the chances for a cure are excellent. These tests, which should be perfected early in the 21st century, will be able to identify molecular genetic changes in the cells of a patient's sputum that signal the presence of lung cancer before it can be detected by X-ray or microscopic examination.

The bottom line: From the biologic standpoint, we've made enormous progress, but are just beginning to see the payoffs in clinical results. Because of that progress today, I expect that by the year 2020, we'll see some very striking and very significant changes in the distribution of cancers, a lower death rate from many cancers, and vast improvements in the way we fight them. 

Martin D. Abeloff, M.D., is the Eli Kennerly Marshall Jr. Professor of Oncology and Director of the Johns Hopkins Oncology Center.

Fatigue Most Common Side Effect

Of all the commonly reported symptoms of cancer patients, fatigue tops the list. Between 72 and 95 percent of cancer patients will experience excessive tiredness as a result of the disease or treatment, according to the National Cancer Institute. And cancer fatigue does not subside with sleep or rest.


It's normal to experience short-term tiredness as the physical and psychological stresses of dealing with a serious illness take their toll. But some cancer patients experience long-term or chronic fatigue, which can last a

month or longer. In some cases, it can last years.

The exact cause of chronic cancer fatigue is unknown. Scientists have suggested several possible influences, including impaired nerve function, anemia, interruption of normal cell function, changes in the way the body metabolizes food, different sleep or breathing patterns, depression and anxiety.

Overwhelming fatigue is frustrating and can have serious consequences. Healthy people may not understand why the fatigued patient can't just rest and feel

better. Family members and friends may accuse the patient of malingering and relationships can become strained. The patient's sense of well-being and self-esteem can fade. And if the fatigue is so great that employment is not possible, financial difficulties and loss of health care benefits can result.

Fatigue due to cancer or treatment should always be reported to a doctor. There may be some medical reason for the fatigue that can be corrected with medication, or counseling may help alleviate anxiety or depression. 

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Cancer Perspectives

perfectly manicured lawn. This means that we have two main issues to deal with: digging up the dandelion plant, and worrying about the seeds that might have escaped and spread before you got there. Obviously, we would prefer to find a cancer at the earliest stage – a young dandelion that hadn't yet bloomed and whose roots aren't too deep. Once the cancer is long-standing and advanced, the problem is more difficult. It's not impossible to get a weed-free lawn, but you'll always have to be watchful to make sure the problem doesn't crop up again.

Dr. DeWeese: I tend to think more in terms of mechanics. Our cells generally have very precise checks and balances to their growth. They grow and then stop growing on a specific schedule. It's a bit like the functioning of a car – it goes when you press the accelerator and stops when you step on the brake. With cancer, for whatever reason (and it can vary between types of cancer), either the accelerator is stuck so cells just keep growing, or the brake pedal isn't working so cells don't stop dividing. When cells grow too quickly, they sometimes don't repair damage in their DNA. If too much damage accumulates, the cells can become even more aggressive and start to spread. So cancer is a combination of having cells that grow too quickly or do not stop growing, and also accumulating other kinds of mutations that allow the cells to become even more aggressive and start to invade other parts of the body.

Should patients change their lifestyles once they are diagnosed?

Dr. Dooley: We in the cancer community call that “foxhole religion” – when patients try to make up for all the real or imagined wrongs they've committed against their bodies. In extreme cases, this can lead to some very interesting behaviors, such as drinking several quarts of broccoli juice a day. More often, patients try different diets such as macrobiotic diets or vegetarianism, or they start taking nutritional supplements. We have no idea whether these measures will work, so I can't recommend them, but neither can I fault anyone for their choices. Patients need to do whatever they feel will help them live longer and not be sick.

Dr. DeWeese: There's not overwhelming data that these kinds of dietary changes can reverse existing cancer. On the other hand, they certainly might help prevent the cellular changes that might cause cancer to begin with. As long as the diets aren't so extreme that they become unhealthful, lifestyle changes certainly can be beneficial to the cancer patients' overall health, making it easier for them to go through treatment. Plus, data suggest that these kinds of lifestyle changes may modify how well cancer grows. In fact, I'm in the process of studying certain nutritional supplements to modify some of the damage to DNA that may play a role in prostate cancer.


What are the main issues for the future?

Dr. Dooley: I think that the major focus for the future needs to be on prevention and early detection. To do this, we need to focus our research efforts on understanding the very

early steps in cancer development, when it is in the precancerous stages. We have very effective treatments already for those types of cancer.

As for cancer treatment, our standard approaches with chemotherapy drugs have given us some benefits, but they are fairly limited. In the future, instead of looking for the “penicillin of cancer” or the magic bullet, we're probably going to be talking about integrating multiple different treatments to treat cancer – much more complicated combinations of drugs, surgery and radiation instead of just giving the same type of drug month after month.

Dr. DeWeese: The promise for the future lies in the tremendous strides we've made in understanding some of the genetic underpinnings of cancer. That information can help us not only treat cancer, but prevent cancer from occurring in the first place.

We're on a precipice of knowledge about how to use this genetic information to make cancer vaccines or cancer-killing viruses that are specific to a particular patient's cancer. In the next 5 to 10 years, we'll be seeing genetic information incorporated into standard therapies, so we may see gene therapy used along with chemotherapy, radiation and surgery. 

William C. Dooley, M.D., is Director of Johns Hopkins Breast Center and Chief of Breast Surgery at the Johns Hopkins Oncology Center.

Theodore L. DeWeese, M.D., is an assistant professor of radiation, oncology and urology at the School of Medicine.

Cancer and Work



— How to protect your job when illness strikes.

by Laurice D. Royal, Esq.

When you receive the news that you have a potentially life-threatening illness, the last thing you may consider is the impact it may have on your job. But if staying in the workforce is important to you, arming yourself with knowledge about your employment rights and obligations is your best protection.

The Americans with Disabilities Act (ADA) safeguards qualified individuals with a disability (including cancer), against, among other employment related actions, discrimination in hiring and firing, promotions, pay, job training, and use of benefits such as paid time off or medical insurance. Under the ADA, which applies to all employers who employ 15 or more employees, an employer cannot take adverse employment action against an employee simply because the employee is ill with a disabling condition, or because the employer's insurance costs may increase due to the need for treatment.

The ADA covers employees who:

- ▶ Have a permanent physical or mental impairment that substantially limits one or more major life activities, such as walking, breathing, seeing and working;

- ▶ Have a history of such impairment;
- ▶ Are regarded as having such an impairment; or
- ▶ Are associated with a person having a disability.

The ADA requires an employer to make a reasonable accommodation to enable a disabled employee to do his or her job, provided that he or she can perform the essential (fundamental) functions of his or her job, satisfy any

prerequisites attached to the job and meet any production or performance standards required of all job incumbents. Accommodations may include, among other things, job restructuring, time off or reassignment to a vacation position.

The Family Medical Leave Act (FMLA) requires employers who employ 50 or more workers to grant up to 12 weeks of unpaid, job-protected time away from the job each year due to, among things, a serious health condition. To qualify, an employee must be employed by the employer for at least 1 year and have worked for 1,250 hours during the year. If an employee meets these requirements, he or she is eligible to take leave to care for his or her own serious health condition.

Should You Tell?

- ▶ An employee who elects to utilize paid time off is usually under no legal obligation to disclose a cancer diagnosis to his or her employer. But concealing the illness and any disability caused by the illness and or the need for treatment may not always be in the employee's best interest. Frequent absences can subject an employee to disciplinary action, up to and including discharge. This may not be the case, however, if the illness or disability is protected under the ADA or FMLA.

Laurice D. Royal, Esq., is Senior Counsel for Employment Affairs at Johns Hopkins.

Resources

The Legal Information Network for Cancer (LINC)
Phone: 800-388-LINC
<http://law.richmond.edu/linc/adact.htm>

Patient Advocate Foundation
Phone: 800-532-5274
www.patientadvocate.org/paf/natlresources.html

National Cancer Institute
Phone: 800-4-CANCER – www.nci.nih.gov

National Coalition for Cancer Survivorship
Phone: 888-650-9127 – www.cansurvivorship.org

U.S. Department of Justice
ADA Information Line – Phone: 800-514-0301
www.usdoj.gov/crt/ada/publicat.htm

American Cancer Society
Phone: 800-ACS-2345 – www.cancer.org

Resources

Books

Breast Cancer Survivor's Club: A Nurse's Experience. Lillie Shockney. Windsor House, 1997.

Love, Medicine and Miracles: Lessons Learned About Self-Healing from a Surgeon's Experience with Exceptional Patients. Bernie S. Siegel. HarperPerennial, 1990.

Peace, Love and Healing: Body-mind Communication and the Path to Self-Healing. Bernie S. Siegel. HarperPerennial, 1990.

How to Live Between Office Visits: A Guide to Life, Love and Health. Bernie S. Siegel. HarperPerennial, 1994.

The T-Factor Diet. Martin Katahn. Bantam, 1994. (for information on low-fat diets)

Chicken Soup for the Surviving Soul: 101 Stories of Courage and Inspiration from Those Who Have Survived Cancer. Jack Canfield. Health Communications, 1996.

The Wellness Community Guide to Fighting for Recovery from Cancer. Harold H. Benjamin. Putnam, 1995.

Web Sites

National Cancer Institute: Information for People with Cancer. http://rex.nci.nih.gov/PATIENTS/INFO_PEOPL_DOC.html Comprehensive information about specific types of cancer, treatment, clinical trials, and living with cancer.

Johns Hopkins Breast Center.
<http://www.med.jhu.edu/breastcenter> Online

breast cancer newsletter (Artemis), survivor stories, news.

National Library of Medicine's MEDLINEplus.
<http://www.nlm.nih.gov/medlineplus>. Directs consumers to health resources. Offers access to information on specific health topics, dictionaries, on-line publications, and MEDLINE – the online medical journal abstracts doctors use.

Centers for Disease Control and Prevention (CDC): Cancer Prevention and Control.
<http://www.cdc.gov/cancer/index.htm> Fact sheets, publications, and links to other cancer-related web sites.

Cancer Care, Inc.
<http://www.cancercareinc.org>

Survivor's Story

accounts for about 70 percent of cases of breast cancer.

As she listened to the doctors at the Hopkins Breast Center, Celeste, then 50, thought about her two young nieces, and how she didn't want them to see her weak and withering. She thought about her twin sister, Clem, with whom she lives and who, of course, was with her at both the mammogram and resulting consultation – writing down everything the doctors said. She thought about her mother, the strong woman whom she didn't want to see weakened by the news.

Mostly, she was thinking about what she had believed until then about breast cancer – how it is a slow, agonizing walk into a tunnel with no light at the end.

But on that day, as Celeste was thinking about all these things, she learned she would take a journey that would lead to a surprising place: a unique sorority of breast cancer survivors. “The moment you begin treatment,” she says, “you are a survivor.”

The doctors told her the journey would be long and hard. They had 8 weeks from the time of diagnosis to begin her cure and ensure her seeing the light at the end.

The first step was a mastectomy, to remove her left breast, which had two sites of cancer. Next came reconstructive surgery, in which fat and muscle would be removed from her abdomen and transferred to give her a more natural-looking breast than a prosthesis. The mastectomy and the reconstructive surgery occurred the same day. Chemotherapy came 5 weeks after surgery.

“The single worst day of my treatment was the day I lost my hair from the chemo,” says Celeste, supervisor for foreign languages at the Howard County Public School System in Maryland. “It wasn't wonderful hair, but it was mine. And it was the first outward sign that there was something wrong. Up until then, I could walk down the street and no one knew I was a breast cancer survivor.”

It wasn't the baldness, really. Rather, it was the “outward sign” that invites the “concern” of others.

“Your first instinct is to not share

news about your cancer with others. I remember one teacher telling me that everyone had known about my cancer and how sorry they were. It was like they were determining who would go to my funeral. It was like I was a reminder that it can happen to them.

“

The single worst day of my treatment was the day I lost my hair. It wasn't wonderful hair, but it was mine. And it was the first outward sign that there was something wrong.

”

“But what I learned from the doctors is that your cancer is just that – yours. You own it, and therefore, you control it, if you become an active participant of the team. We think of this big thing called ‘cancer’ that is then broken down to breast cancer, and then further broken down to invasive ductal carcinoma and other types.

“Once you make that decision, you realize that your breast cancer – your invasive ductal carcinoma – is not necessarily the same as someone else's. What happens to them isn't necessarily going to happen to you. Some of it may happen, some of it may not.”

With that knowledge – coupled with the information Celeste got from reading books recommended by the Breast Center staff – came the ability to enjoy the ice cream sundaes brought by visiting friends or watch a baseball game, instead of dwelling on the horror stories of what happened to someone's friend who had breast cancer 20 years ago.

“Having support is important, and luckily, I got a lot of support from the wonderful people in my life. But you also learn as a survivor that you must make plans – whether it's to watch a baseball game or to attend that Thanksgiving dinner. In my case, it wasn't enough to just attend the dinner. I made it a point to decide where everyone was going to sit!”

While making those holiday dinner plans, Celeste got more devastating news: She had contracted uterine cancer – just a year after being diagnosed with breast cancer. “I was angry for all of 30 minutes because I had just completed chemotherapy for breast cancer. But the chemo I had was designed to kill only breast cancer cells. So after those 30 minutes, I simply said, ‘Now what?’

“It was easier to take because I had been through breast cancer. My biggest concern was if I would have to get more chemo, and if I did, would it be hair-sparing? Dr. Fredrick Montz, division director of gynecologic oncology, who has a ponytail, said he doubted I would need chemo, but if I needed it and it wasn't hair-sparing, he would give me his hair. That remark made all the difference to me, and I was able to go through my uterine cancer surgery, knowing I would be just fine.”

Today, Celeste Carr is feeling fine and has returned to the life she had before Sept. 12, 1997. She's back at work, exercising daily on her treadmill, watching her beloved Orioles and planning holiday meals. But there are some changes that result from walking through the tunnel and seeing the light.

“I never lost my belief in God through all of this and now, it's gotten stronger. I've learned that my mother was right when she said things were going to be all right because she and others were praying for me. My sister, Clem, and I now eat broccoli and citrus fruit every day, for both lunch and dinner. I never miss a mammogram appointment. And I've learned that you must be willing to share your experience with others,” says Celeste, who volunteers to counsel and support other breast cancer survivors at Hopkins and elsewhere.

Support Groups



— Participation can be a big help in coping with a cancer diagnosis.

by
Carole F. Seddon, LCSW

For some, participating in a support group can be a big help in coping with the diagnosis of cancer. These groups provide a sense of kinship among members who, along with you, have a firsthand knowledge of what it's like to be a cancer survivor. Support groups come, however, in many shapes and sizes. There are groups led by a facilitator who is also a cancer survivor, while other groups are led by professional staff who have no history of cancer. Some are discussion groups, whose membership is limited to cancer patients, with topics brought up by those attending the meeting. Others can be a mixture of patients and families and may have preset topics. There are also educational groups where there is little to no group discussion but rather speakers who talk and answer questions on a specific topic. Regardless of the type, support groups have demonstrated that they help those who attend by providing that sense of kinship and by supplying a wealth of information on issues of concern to those living with cancer. Topics can range from how group members use the Internet, for instance, to how they communicate with medical staff, family, or friends, to how they manage feelings and

more, much more.


If you're interested, it's best to attend a meeting or two before deciding to stop looking for another group. If you find after a couple of meetings that the group doesn't meet your needs or just doesn't "feel" right, trust your instincts and move on. Your physician or the hospital's social worker can help you find others.

Here at the Johns Hopkins Oncology Center, we have support groups that are designed specifically for patients with breast and prostate cancers, for patients who have received a bone marrow transplant, and for caregivers of cancer patients in the hospital. There is a general educational series that provides specific information on different topics of interest to cancer patients and family members "living with cancer." We also have special support groups for children who have a parent, grandparent, brother, or sister diagnosed with cancer.

You shouldn't feel pressured to join a group, since they're not for everyone. You may not feel comfortable in a group setting. For instance, some people just don't like speaking in a group. Others have told me they feel too vulnerable and emotionally

fragile to risk hearing anything negative or frightening. These patients may get more out of talking one-on-one with another cancer survivor or with a counselor or therapist.

Most patients use a support group for only a limited time. Some seek out a group immediately after diagnosis or surgery; others do so during chemotherapy and/or radiation while still others wait until treatments have ended. A number of patients have told me about their decision to get involved in organizations where they provide volunteer services for newly diagnosed cancer patients or work politically to raise money for cancer research. These activities seem to be empowering and help them to feel that they are continuing in their fight against cancer.

Whatever methods you choose to use to help you cope with this stressful time in your life, it is important to know that help is available and is yours for the asking. 


Carole F. Seddon, a licensed clinical social worker, is Clinical Coordinator of the Cancer Counseling Center at the Johns Hopkins Oncology Center.

One is a young teacher who goes to work each day with a scarf or hat on her head and a great burden on her shoulders. Several months ago, at 29 – while planning her wedding and in her first year of teaching Spanish for Howard County schools – she was diagnosed with breast cancer.

She was angry and terrified. Then she met Celeste Carr, who shared with her more than just the same employer.

Celeste told her about her tunnel and the many roads it would take: The mastectomy and breast reconstruction surgery. The chemotherapy. The vomiting and pain and having to be bathed and not being able to walk the stairs or lift things. The walk into the doctor's waiting room, knowing that every other woman sitting there is going through a similar journey.

One day the two were talking when the teacher broke down, weeping. "I knew there was a reason for my coming to Howard County," she told Celeste. "I know that God had a plan for me, to have me go through this experience. I think it was to meet someone like you to talk to."

They walk the tunnel together. 

Side Effects of Cancer Treatment



Like the disease, they are very individual.

by
Antonio C. Wolff, M.D.

To combat an aggressive disease like cancer, treatments need to be very powerful. But potent therapy is often accompanied by equally potent side effects.

Different chemotherapy drugs produce different sets of possible side effects; even the same drug in the same dosage will affect different people in different ways. Still, certain side effects are common and there are ways of dealing with them to minimize their effects on patients.

Fatigue

What causes it?

While its cause is not fully understood, fatigue is a major symptom of cancer. It is also a major side effect of chemotherapy. Some chemo drugs – such as cisplatin (*Platinol*) – cause more fatigue than others. Individual degrees of fatigue vary, as some patients are able to continue working and maintain normal activities of daily living, while others may be debilitated.

Recommendations: The harder you push to maintain a normal schedule, the more fatigued you may feel. So reduce the demands on your limited stamina and try to take it easy. There are no specific vitamin or nutritional supplements that can improve energy.

Important to know: Fatigue may be due to anemia caused by both the disease and the chemotherapy. This symptom is often ignored by physicians, but can be treated if recognized. If the levels of red blood cells fall too low, you may be helped by transfusions of red blood cells or possibly by the use of the red-blood-cell growth hormone erythropoietin.

Hair Loss

What causes it?

Along with killing cancer cells, some treatments can temporarily damage normal cells that are growing, dividing and continuously

regenerating, such as cells in hair follicles. Usually about 2 weeks after treatment begins (but sometimes as early as after the first treatment), the follicle cells are damaged enough to allow the hair to fall out. Radiation to the brain can cause hair loss, as can many chemotherapy drugs.

Recommendations: Not much can be done about hair loss. When it happens, it is usually very dramatic, as if someone came in and cut your hair off at the roots. Some patients get up in the morning and find their pillow covered with hair, or their hair drops off in the shower. To minimize the trauma:

- ▶ Ask your doctor ahead of time if your treatment has a high incidence of hair loss so you know whether to prepare.
- ▶ At the end of the first week of treatment, get a very short haircut. This way, it won't be so startling when the hair falls out.
- ▶ Some patients don't seem bothered by the hair loss. Some use it as an excuse to change their look, or they prefer to use scarves or hats. Don't feel the need to wear a wig if you're not comfortable with it.
- ▶ If you choose to wear a wig, order it even before your first treatment. If you see a wigmaker while you still have your hair, your normal color, texture and length can be matched quite well.
- ▶ Remember that hair will grow back after treatment is stopped.

Important to know: Some people recommend wearing a "cold cap" to prevent hair loss. The idea is to decrease the temperature of the scalp, causing blood vessels to constrict, which in turn prevents chemotherapy from getting to the scalp, and saves hair follicles from damage. This is not a good idea. There have been cases where people developed skin metastasis later, because chemotherapy did not reach all areas of the skin.

Mouth Sores

What causes them?

Along with their ability to kill cancer cells, chemotherapy drugs can

also damage normal cells that normally grow and rejuvenate continuously. These cells are found in hair follicles and in the digestive tract, including the mouth, throat and intestines. In the mouth, some chemotherapy drugs can cause increased sensitivity and mouth sores.

Recommendations:

- ▶ Before chemotherapy, visit your dentist to get any necessary dental work done, including routine cleanings and to make sure you don't have any active gum disease or tooth infection. Chemotherapy decreases an individual's immune defenses, so even small infections normally kept in check by the immune system may flare up.
- ▶ Be obsessive about oral hygiene while undergoing chemotherapy. Brush teeth after every meal with a very soft toothbrush and a regular, non-abrasive toothpaste. If gums are too sensitive, rinse often with plain water.
- ▶ Do not use whitening or high-abrasive toothpaste, and do not use a mouthwash that contains alcohol. These will make the mouth more sensitive. Regular mouthwashes without alcohol can be used.
- ▶ There are prescription medications that can make your mouth less painful. These function as a lubricant or a topical anesthetic to help numb the mouth.

Important to know: See your doctor if sores develop. Since chemotherapy depresses the immune system, mouth sores sometimes can be a sign of an infection, such as the fungal infection candidiasis, or a viral infection, such as herpes simplex. If mouth sores are caused by an infection, physicians can prescribe an anti-fungal or anti-viral medication.

Dry Mouth

What causes it?

Dry mouth tends to occur most often in response to radiation treatments to the head and neck. Radiation can cause temporary or permanent damage to salivary glands,

which in turn causes a decrease in the production of saliva. Without a constant production of saliva, the mucous membranes of the mouth become dry and can ulcerate.

Recommendations: Ask your doctor for a prescription to treat dry mouth.

- ▶ When the damage to salivary glands is not too severe, certain medications can boost production of saliva from salivary glands that are still functioning.
- ▶ Saliva substitutes are also available by prescription. These are oily liquids that can be swished in your mouth a few times a day to keep the mouth wet.

Nausea and Vomiting

What causes it?

Nausea and vomiting can have two main causes. Stimulation of specific sensory terminals in the small intestines, such as when nerves are damaged by chemotherapy or radiation, can trigger it. But there is also an area in the brain called the chemoreceptor trigger zone that controls the nausea and vomiting reflex, which can be stimulated by some drugs. Although nausea is mostly associated with chemotherapy, radiation can also cause nausea if given in the abdominal area, such as for tumors of the pancreas, stomach or intestines.

Recommendations: Nausea and vomiting are not as much of a problem as they used to be, thanks to new medications, including ondansetron (*Zofran*) and granisetron (*Kytril*). Given by vein or by mouth, they can dramatically reduce, and sometimes eliminate, the incidence of nausea and vomiting. This effect is even stronger when a steroid called dexamethasone (*Decadron*) is also given. There is virtually no reason for anyone to suffer from nausea and vomiting from cancer treatment any more.

Important to know: These drugs are most effective if given before receiving chemotherapy. Some people who experience severe nausea and vomiting after one treatment develop anticipatory nausea, where they feel

sick before the next treatment. If your chemotherapy drug is likely to cause nausea and vomiting, ask your doctor for an antiemetic drug before your treatment.

Diarrhea

What causes it?

Diarrhea can be caused by both chemotherapy and radiation. Cells on the surface of the intestines are constantly being renewed. Chemotherapy and radiation can kill the cells that form the intestinal lining, and sometimes temporarily halt production of new lining cells. When the intestine loses its lining, it consequently loses its ability to secrete and reabsorb the intestinal juices that are necessary for normal digestion and absorption of foods. Fluid from the walls of the intestines can seep into the intestine, and cause diarrhea.

Recommendations: There's nothing that can prevent it. If you experience diarrhea, tell your doctor right away. Medications, even over-the-counter medications such as *Lomotil*, can prevent worsening of the symptoms if given early on.

Important to know: Severe diarrhea can lead to dehydration, which can be dangerous in people who are already battling cancer. This is particularly important in the elderly, who sometimes may require intravenous hydration. In some cases, chemotherapy dosages will need to be reduced to get diarrhea under control.

Fever and Infections


What causes them?

Fever and infections can be caused by bacteria or viruses that invade the body when the immune system is lowered because of chemotherapy. Many chemotherapy drugs can suppress bone marrow cells. When bone marrow is functioning properly, it produces white blood cells, which help the body fight infections, and creates red blood cells and platelets. At the end of the first week after each chemotherapy, patients enter a period when there's a high chance that their white blood cell count will be very

suppressed. In most cases, the patient has no problems. But approximately 5 percent of patients develop a fever above 100.5, a sign that an infection may have taken advantage of the weakened immune system.

Recommendations: Take your temperature once or twice a day, beginning at the end of the first week of chemotherapy, or if you're feeling sick. If you have a fever, contact your doctor no matter what time it is, even nights or weekends. You may be asked to have blood drawn for a blood count. If your white blood cell count is low, you may also undergo urinalysis, chest X-rays and further blood analysis, and you'll most likely be put on antibiotics. The cause of the infection may never be discovered, but giving prophylactic antibiotics can prevent the development of complications, particularly septicemia – a life-threatening infection.

Patients who develop this problem may need to have their chemotherapy dose lowered in the next cycle. If it's important to maintain a regular chemotherapy dose and schedule, patients may be given injections of a white blood cell growth hormone to keep their blood levels high.

Important to know: The type of infections that take hold usually originate in your own body – not something you catch from someone else. For example, when chemotherapy drugs damage the lining of the intestines, it becomes easier for our own intestinal flora – including some organisms that can cause damage – to go through the intestinal wall into the blood stream. This can cause a systemic infection, which is first indicated by a fever. Sometimes viruses that had been dormant in our bodies for many years can be reactivated and cause infections, like shingles (the varicella-zoster virus) and fever blisters (the herpes simplex virus). These infections can be treated with anti-viral drugs. 

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An Informed Patient



— Tips for understanding your role in the healing.

by
Michael A. Carducci, M.D.

From the day you receive a diagnosis of cancer, life becomes a series of decisions: which doctor to choose... what type of treatment to get... when to tell your family. The questions will change throughout your treatment, but the answers will all have one common denominator – you.

The patients who do best are those who understand themselves and find a way to make their treatment fit their personal style. Everyone's approach to healing will be different. Some people like to research their disease and read medical journals, while others may prefer to rent an informational video or have a family member explain things to them. The key is to be yourself and live through the experience being the kind of person you want to be.

In order to make the kinds of decisions that are right for you and get the best possible care, you can do several things:

- ▶ **Evaluate your doctor.** Patients can fire their doctors, but doctors can't fire patients. You are in control of deciding whether your physician is the right one for you. You don't have to like your doctor, but you have to trust him or her, and feel that he or she will be an advocate for you. In your first visit, evaluate your doctor against your needs and decide if there is a good fit.
- ▶ **Get to know your team.** Aside from your primary care physician, you may also have interactions with a medical oncologist, a surgeon and a radiation oncologist. Other types of specialists, such as a neurologist or a psychiatrist, may also play a part in your healing. Understand that your interactions with each of these doctors will be slightly different since they each have different concerns.

Many patients are disappointed to realize that their health team may not be communicating as well as expected, and get frustrated at

having to tell their story over and over again. Take the time to talk to each of the members of your treatment team, and take pride in being able to relate your experiences.

- ▶ **Ask your questions.** The only stupid question is the one left unasked. But that doesn't necessarily mean you'll always get the answer you want – or any answer. Determine how important the question is to you, then press for the important ones.

Some patients hear about a new drug or therapy for their type of cancer, but are afraid of insulting their doctor by asking about it. It's your right to ask, and to understand why that therapy may or may not be right for you. If the physician can't handle that type of question, you may need a different doctor.

Write down all your questions before your office visit. Make a point of jotting down notes and questions as they occur to you between visits so you don't forget

them. A family member may be the one to take notes as you are intent on listening.

- ▶ **Bring a tape recorder to every office visit.** You may be exposed to a lot of information during your appointment. If you tape-record the visit, you'll have a chance to review the information, make sure that you heard everything, and correct misinterpretations. Ask the doctor prior to taping if he or she has any objections.
- ▶ **Pull in your support.** Cancer is hard to handle alone. People who are normally independent may find they are unable to handle everything by themselves. Early in the process, find a support network you can rely on, and use it. Talk to friends and neighbors, or ask that a relative be available for help. Support groups, such as those often found in hospitals or through **The Wellness Community**, can help people deal with many of the practical and emotional aspects of cancer. (Call the national office of The Wellness Community, a non-profit cancer support organization, to find out if there is a chapter near you: 1-888-793-WELL.)


Quality Vs. Quantity of Life

Living through the process of cancer can be an incredible time of human growth, even if the body is physically dying. Death is a natural part of life. In the face of that reality, many patients discover that their lives are richer and more beautiful than they were before the diagnosis. It's a time to look around and discover what's important, what needs to get done, and then to do it.

This shift in focus requires patients to ask themselves what they want from their lives, and whether they are willing to fight for quantity of life at the expense of quality of life. It's a tough judgment to make. Each person has different needs and life situations that will help guide the decision. Some factors that are often weighed in the decision are:

- ▶ **Age.** People who have lived a long life often feel that quality time is more important than extra years. Younger people may have specific time goals, such as seeing a daughter get married, that


make quantity of life more important.

- ▶ **Experience with others' cancer.** People who have experienced family members' death from cancer may have specific ideas about what the process is like, positive or negative, that will affect their choice.
- ▶ **Activity level.** *The reason we treat cancer is to keep living and doing the things we want to do.* If illness has progressed to the point where nothing is getting done, where the patient can no longer travel or garden or be social, then maximizing quality of life often becomes the goal.
- ▶ **Comfort level.** Finding quality of life is difficult if treatments are unbearable. If the bottom line is palliation instead of cure, the patient has the right to choose the type of treatment that will make him or her most comfortable. 

► **Keep your doctor informed.**

Cancer treatment is a combined effort by you and your doctor. Your doctor should be someone you trust enough to tell everything about your physical and mental states. Tell your doctor if you are taking new medications or supplements or under additional stress. For example, many patients are turning to complementary therapies – such as herbs, acupuncture or vitamins – as an adjunct to regular

treatments. Although most complementary therapies are harmless, some may actually conflict with regular treatment. Many patients hold this type of information back, thinking that their doctors will tell them to stop. In truth, most doctors want their patients to feel better, and won't discourage complementary therapies unless they are harming the patient's chance of recovery. By keeping a channel of communication open

between you and your doctor, you are helping to ensure that you both get the information you need for optimal treatment. 

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Nutrition for the Cancer Patient

While good nutrition may not cure cancer, dietary factors do play an important role in cancer treatment. When you're battling a serious disease, adequate nutrition is needed to maintain strength and overall well-being, keep the immune system functioning optimally, prevent the break-down of body tissue, and help the body heal after surgery or other treatment. A well-nourished person is better able to tolerate treatment side effects, and may even be able to handle more aggressive treatments.

Good nutrition may also increase odds for survival for people battling cancer. In one study of people with head and neck cancer, the 2-year survival rate was six times higher among those who were well-nourished compared with those with poor nutrition status.

To get the best possible mix of nutrients without too much fat, eat a diet rich in fruits, vegetables and whole-grain foods. Your doctor may have other recommendations specific to your situation, so let him or her know that you are interested in nutrition advice. And don't take any nutritional supplements without discussing it with your doctor, since certain supplements may interfere with some chemotherapy drugs.

Problems Specific to Cancer

Nutrition can be a problem for people with cancer for several

reasons. The cancer itself may interfere with eating and digestion – there may be difficulty chewing and swallowing, blockages in the gastrointestinal tract due to tumor growth, or interference with digestive enzymes and hormones. Cancer treatments can cause nausea, vomiting, difficulty swallowing or dry mouth, and surgery can make eating difficult. Changes in taste or smell, depression and lack of energy can make a person not want to eat. Appetite and metabolism may change so much that health is compromised.

Eating Tips

If you are undergoing cancer treatment, it's important to be good to yourself. Experiment with the following tips, and use the ones that work for you. Listen to your body to find the foods and eating schedule that make you feel best.


- Find ways to relax while eating. Choose a quiet place, put on soothing music, and try to keep distractions to a minimum.
- Eat small meals throughout the day instead of three big meals.
- Eat foods that are warm or at room temperature.
- Learn which food smells are appealing to you, and use them to stimulate your appetite. Avoid cooking foods with unappealing smells. Eat foods with little or no smell, such as cottage cheese or crackers.

- Add extra calories to your food by adding dry milk, honey, jam or brown sugar whenever possible.

If you are frequently nauseated:

- Avoid fatty, greasy or fried foods; sweets; and hot or spicy foods
- Eat in a well-ventilated, cool room.
- Consume small amounts throughout the day.
- Drink liquids between meals, not while you are eating (except for small amounts to moisten food if your mouth is dry).
- Don't force yourself to eat during nausea.
- Eat in a room other than the kitchen – cooking smells may make your nausea worse.

If you are having physical trouble with eating due to cancer or treatment:

- Take very small bites of food at a time instead of full mouthfuls.
- Cook foods until they are very tender or even mushy.
- Puree foods in a blender or food processor.
- Mix foods with broth, sauces or thin gravies to make them easier to swallow.
- Drink through a straw if that makes it easier. 

Breaking the News



— How to reveal news of your diagnosis to those close to you.

by Carole F. Seddon, LCSW

Dealing with a diagnosis of cancer is never easy. The news often comes as a terrible shock, causing a cascade of emotions in both the patient and the rest of the family. One of the issues that usually arises immediately is how to tell others. What do you say to your children? Your boss? Aged parents? Friends and neighbors?

Many patients tell me that breaking the news of a cancer diagnosis is like reliving the moment when they first heard about their illness. Some, however, find relief upon reaching out to close relatives and friends. Sooner or later, nearly all patients share at least some of the information about the diagnosis and impending treatment with close relatives and friends as well as their boss.

Keeping in mind that there are no rules, no “one size fits all” formula for breaking the news, here are some guidelines that may help:

Telling Children

Patients worry most about how – and how much – to tell their children. Obviously, what you say depends on the age of your children and how much they’re capable of understanding. Toddlers can only understand the most rudimentary explanation, such as, “Mom is sick and is going to the doctor to try to get better.” These children more often react to the emotions of the people around them and to their separation from caregivers. The best thing you can do for them is to keep their routines and any changes in caregivers to a minimum, whenever possible.

Youngsters and elementary school-aged children will worry less if they know what to expect in terms of a hospital stay, surgeries, medical care and who will be taking care of them while treatments occur. You don’t have to be overly detailed or they may be overwhelmed with more

information than they can tolerate, but you should inform them of your willingness to answer any and all of their questions no matter how many times they need to ask them.

Children 3, 4, 5 or even 6 years of age often worry that they did something to cause the cancer. Although they may not voice their fears, it is important to let them know that they are not responsible. Similarly, children around 8 to 12 years of age may worry that they can catch the cancer or that the other parent may catch the cancer. So some reassurance is required on that score.

For toddlers, anxiety may be lessened by letting them see your hospital room or by bringing them with you when you go to the doctor.

Adolescents, especially if the oldest of the children, often have to take on some of the parental responsibility. It is important to let them be teenagers whenever possible while also being very honest with them in answering their questions.

Telling Your Employer

Sooner or later, you will have to tell your boss or supervisor, if only because you may be absent from work for a while or may be unable to do the same amount of work on all days. It is a general rule of thumb to be honest with your boss; he or she needs to know what to expect so to plan for coverage. When possible, however, it is helpful to wait until you have all the information about your treatment so you can explain, in concrete terms, how much time off you’ll need and why. If you’re worried about losing your job because of illness, talk to the hospital social worker about your rights under the Americans with Disabilities Act (see related story on page 5).


What you tell co-workers depends on how close you are to them or how much you feel the need to influence

the gossip in the office. You don’t have to tell anyone the details of your treatment.

Telling Friends and Family

Most people have a spouse, other family member or close friend with them when they get their diagnosis. That is pretty hard to do alone. However, how you tell your extended family and your friends depends upon how comfortable you are discussing your illness. You can always delegate the responsibility to your spouse or another loved one. If you’re active in a church or a synagogue, you can ask the priest, rabbi or minister to break the news.

Aged parents may assume that all cancer is terminal, so be sure to accentuate the positive when telling them. Emphasize that treatments have improved and relay the positive things the doctor has told you about the possible outcome of your treatments as well as negatives.

It can be helpful, whenever possible, to share your feelings and fears with close relatives and friends and to let them share theirs. Many patients and family members believe they must be protective of each other by hiding how scared they are. Patients protest that they are “fine” and doing well when they’re not. Some feel guilty that they’re inflicting too much distress on family members. And similarly, close relatives and friends want so much to protect their loved one, the patient, that they never disclose their own fears. But there truly can be real comfort when patient and family share their feelings with each other so that no one has to feel alone and isolated during this difficult time. 

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