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New Answers for **CANCER**

Cutting-edge drugs and research are helping solve the puzzle

Cancer Resource Guide

Where to turn for help

Stem Cells

The real culprits?

The Cancer Genome

Mapping out an attack plan



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Living with Cancer

Keep up your spirits and tap available resources to make the disease manageable

By Lisa Stein

Overview

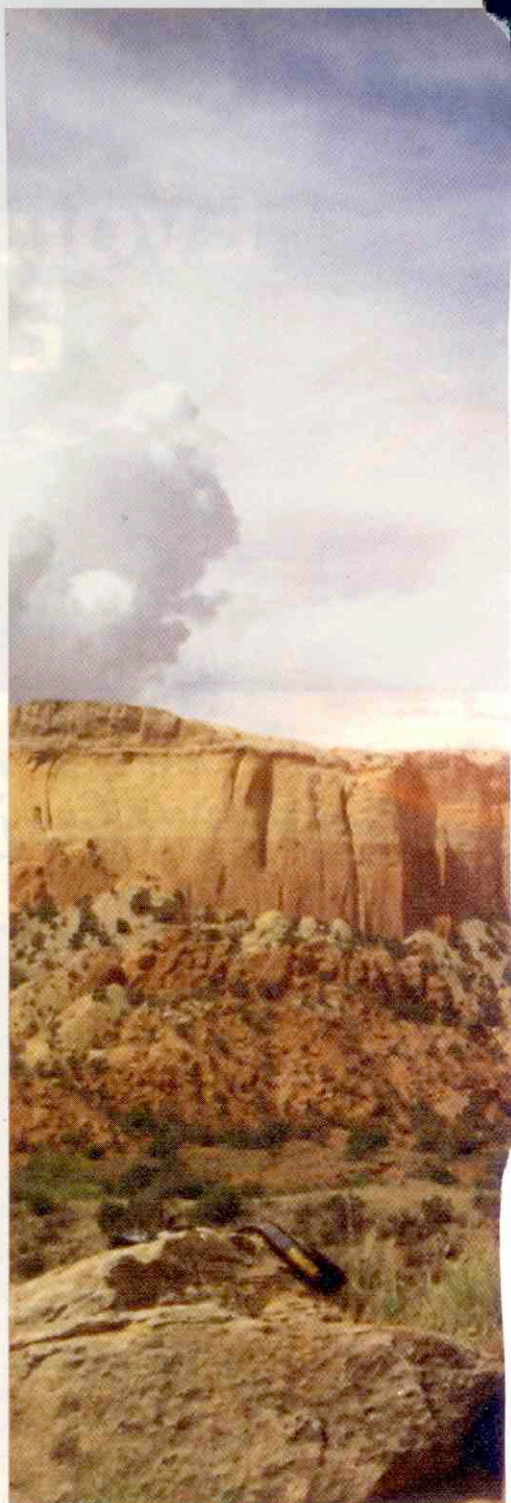
- Rather than surrendering to despair and impersonal medical treatments, growing numbers of cancer patients are empowering themselves with information and control over their therapies. The trend is finding acceptance in mainstream medicine and helping people with cancer lead healthier lives.
- The experiences of author and filmmaker Kris Carr, who was diagnosed with a rare, incurable malignancy, illustrate how successfully one can manage cancer as a chronic disease.
- The following resource guides offer tips on developing a strategy for managing the illness, asking the right questions of physicians and getting the right professional and personal support.

It was February 2003, and Kris Carr, a photographer and actress, was on a roll. The bubbly, green-eyed stunner was in high demand. She was considered “the Julia Roberts of advertising” (at least according to her agent), thanks to her success in two popular Bud Light commercials that aired during the Super Bowl. She also had some impressive theater and film credits, among them a role in Arthur Miller’s *Mr. Peter’s Connections*, in which she performed (in the buff, no less) alongside actor Peter Falk.

Like many of her hip young compeers, Carr, then 31, routinely burned the candle at both ends. She existed on energy bars, fast food and coffee downed between nonstop auditions and takes. Every so often her frenetic lifestyle would catch up with her as it did now: she had just returned home to New York City after “partying like a rock star” at Florida’s Sarasota Film

Festival, where a film she had appeared in premiered, and she was dragging. Time to detox, cleanse her body and soul, exercise and eat right for a spell. She swore off drinking for a month and took a vigorous Jivamukti-style yoga class to kick-start her new get-healthy-quick scheme.

“The following morning I woke up feeling like I was hit by a truck,” Carr



LISA COCCIARDI (photograph)

"I DON'T THINK anyone has a better life than me," says cancer patient Kris Carr.



You Have Cancer: Now What?

Diagnosis: cancer. Your head is spinning, and you feel like the wind has been sucked out of you. In a split second, life as you knew it is gone. "Getting diagnosed throws your entire universe into a free fall," Carr writes in her 2007 book *Crazy Sexy Cancer Tips*. "There's no sugarcoating it: cancer is a devastating blow, one that takes time to process."

The first things you should do (after taking a deep breath and trying to chill):

Find the best doctor for your disease: Be willing to travel and *always* get second, third and even fourth opinions to make sure that you're getting the best treatment.

Design a healing plan: Pull together a team of Western physicians as well as integrative doctors (to teach you how to build up your immunity and spiritual grit) to create the best get-healthy recipe. Ask family and friends to chip in and scour the Internet and bookshelves for information. "If you want to heal, you have to take initiative, have a voice and use it," Carr says.

Focus on lifestyle changes: "The only thing that you can control is what you eat, what you drink and how you move," Carr says. She recommends exploring healthy diets, exercise and alternative therapies such as massage, yoga and meditation to boost and maintain your physical and emotional well-being.

Create a support system: "Nobody understands you quite like another cancer survivor," Carr says. "There is incredible strength in that."

Live! "Don't wait for permission to live. Just because you have cancer does not mean that your life is over," Carr insists. "Start living. It's that simple."



SERGEY TIMASHOV/istockphoto (all icons)
says. Every muscle ached. She dismissed her sore body as a sign that she was more out of shape than she had thought and, as usual, slipped into tight jeans, slathered on a mask of makeup and headed to an audition: a commercial for a diet shake. (She didn't get it: too fat, says the slender onetime model.)
By evening, stiff muscles were the

least of Carr's problems. Her pain had worsened, and it was now accompanied by shortness of breath and severe abdominal cramping. She made an appointment to see her doctor the following day.

Gallbladder trouble, the physician surmised after a quick examination. Recommended treatment: yank the pear-shaped organ that, when healthy,

helps the liver flush fats from the body but, when faulty, causes excruciating pain. He gave Carr a prescription for painkillers and sent her for an ultrasound to confirm that her gallbladder was indeed the culprit.

It wasn't. "When they did the ultrasound, they found the 'lesions.' They could see there were spots all over my liver—so many that it looked like Swiss cheese," Carr says. She was concerned but still

blissfully ignorant of the potential ramifications. "I didn't know," she says, "that lesions meant tumors."

A battery of tests over the next few days revealed that Carr was suffering from epithelioid hemangioendothelioma (EHE), a vascular cancer in the lining of the blood vessels in her liver and lungs so rare that only 0.01 percent of the cancer population has it. Around 200 to 300 cases are diagnosed nationwide every year. The cause: unknown. The cancer was stage IV—incurable and inoperable, the doctor said. "Some people say it could have come on like a meteor shower," Carr says; others suspect the tumors had been developing her whole life.

EHE is typically a slow-moving cancer. There are studies under way but currently no cures or definitive treatments. The doctor recommended a "watch and wait" approach. That is, that they take their cues from the tumors—monitor them for two months to gauge whether they were holding steady or moving slowly or swiftly. They were quiet for now, "indolent" in cancer-speak, and the hope was they would stay that way.

It was February 14. "Happy Valen-

"How could I live

tine's Day. You have cancer," Carr wrote in her journal that night.

Why Me?

"I FELT LIKE I was punched in the stomach by God," she recalls. "Cancer is such a frightening word. How could this be happening to me? Cancer happened to other people. I was young and vibrant. I was the Bud Girl, for Christ's sake. I felt like I was staring down the barrel of a gun, waiting to find out how many bullets were inside."

There were 24—to be exact—littering her liver and lungs.

Carr pressed the doctor on her options. "Just try and live a normal life," he told her.

With two dozen time bombs ticking



Questions to Ask

Studies show that cancer (and other) patients who arm themselves with

information typically fare better and experience fewer side effects than those who simply follow doctors' orders, no questions asked. Being informed gives them some control over their disease—and that feeling of empowerment plays a role in the healing process. No. 1 rule: do not be cowed by your doctor. Ask him or her to explain anything and everything you don't understand. Prepare questions in advance of appointments (to reduce stress and the odds of forgetting any)—and bring a notebook to jot down answers and other important info. Below are some questions you should ask:



- What causes this type of cancer?
- What are the risk factors? If it's genetic, are other family members at risk?
- What lifestyle changes (diet, exercise, rest) do you recommend?
- What are my treatment options?
- Are there activities that should be avoided because they might trigger or exacerbate symptoms?
- What happens if new symptoms crop up or existing ones worsen?
- What medical tests or procedures are necessary? How often?
- What stage is my cancer? What does that mean?
- What is my overall prognosis or chance of recovery?
- What are the average survival and cure rates?
- Could my disease go into remission?
- What is the recommended treatment?
- How often will I have to undergo treatment—and for how long?
- What are the potential side effects?
- What are the benefits versus the risks of each treatment option?
- Are there alternative therapies? What are they?
- What are the expected results of treatment?
- Is the treatment painful? If so, is there a way to make it more bearable?
- How long is the recovery? Will it require a hospital stay?
- When can I resume my normal activity (if it's been curtailed)?
- Has my cancer spread? If so, how does this change treatment decisions?
- Am I eligible for any clinical trials?
- What happens if my disease progresses while I'm in a clinical trial?
- Who foots the bills if I participate in a clinical trial?
- Where can I find emotional, psychological and spiritual support?
- Whom should I call with questions or concerns after office hours?
- May I contact you or a nurse if I have questions or more symptoms? (If the answer is "no," find another doctor.)

inside her? “How the hell could I do that? How could I live with cancer without thinking of dying every day?” she wondered.

Well, he offered, she *could* try to strengthen her immune system through diet and lifestyle changes.

“He did not know it, but in that moment he planted the seeds for personal revolution,” Carr says. “I was not going to kick back and wait for the unknown. I was going to dive in and become a full-time healing junkie.”

She set about trying to find out everything she possibly could about cancer. She sought second, third and fourth opinions. “If I had listened to one of the first doctors I talked to, I would have ended up sliced, fried and hauling around not one but three organs that didn’t belong to me,” she says.



Becoming a “Healing Junkie”

CARR HIT THE BOOKS and the Internet. (“I tell people I have a Ph.D. from Google University,” she says, laughing.) She traded in fast food for a vegan diet and swapped martinis for a green brew of cucumbers, kale, celery

and sprouts. She formed a “posse” with other young women with cancer. She explored alternative therapies, including massage and meditation, and even spent time in a Zen monastery. And she began the empowering process of documenting and filming her journey—ev-

AFTER DOCTORS found tumors in her liver (below left), Carr hit the books to learn more about her disorder.



with cancer without thinking of dying every day?”



Your Odds of Beating Cancer

Success in the battle against cancer is often measured in terms of the “five-year relative survival rate.” That rate is the number of patients who are still alive five years after being diagnosed, relative to the number who would be expected to survive if they had not come down with the disease. Five years might not seem like a lot, but it is, considering that 67 is the median age for diagnosis.

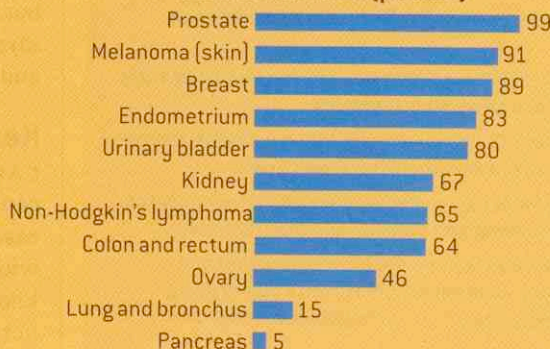
Below is a sampling of five-year relative survival rates for common types of cancer diagnosed between 1996 and 2004. These rates are calculated by the National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) program,

which collects survival data from state registries covering about 26 percent of the U.S. population.

Survival rates have increased dramatically over the years, thanks to earlier detection and better treatments. The five-year relative survival rate for patients diagnosed with any type of cancer in 1975 was 50 percent; the rate jumped to 67 percent in 2000.

Bear in mind that survival rates vary widely depending on the type of cancer and the patient’s age, gender, general health, lifestyle and ethnicity. You can find more detailed statistics at <http://seer.cancer.gov>

Five-Year Survival Rates (percent)





Getting Support: Tips, Tools and Tenderness



You've just been diagnosed with cancer. Now what? First and foremost, do not try to handle this on your own. Allow family and friends to help, and find others in your situation to lean on.

Online resources:

- www.crazysexcancer.com: Carr's Web site. Have questions? Want to dish? You can visit her online community, www.crazysexcylife.com.
- <http://berniesiegelmd.com> and www.ecap-online.org: These sites of physician Bernie Siegel, author of *Love, Medicine & Miracles* and *Peace, Love & Healing* (both from Harper Paperbacks, 1990), offer info and

tools based on the science of mind-body-spirit medicine.

- www.cancercare.org: Need a professional cancer assistant? Try the next best thing. This site is designed to help patients navigate their way through cancer—answering questions, finding help or just “listening” when they need to vent.
- <http://nccam.nih.gov>: The National Center for Complementary and Alternative Medicine of the National Institutes of Health provides information here on alternative and complementary therapies, discoveries and clinical trials.
- <http://hippocrateshealthinstitute.com>: Site of the Hippocrates Health Institute, a world-renowned healing center in Florida.
- www.mercola.com: An alternative medicine and education site.
- www.heardsupport.org: This site is specifically geared toward patients with hemangioendothelioma, the rare cancer that Carr has.
- www.livestrong.org: Site of seven-time Tour de France winner and cancer survivor Lance Armstrong.
- www.ulmanfund.org: Provides support programs and resources for patients and their families. Also helpful: a downloadable book penned by founders Doug and Diana Ulman.
- www.thechinastudy.com: *The China Study*, by T. Colin Campbell, probes the relationship between diet and cancer and other diseases.
- www.cancer.gov: This site of the National Cancer Institute is a comprehensive source of state-of-the-art treatments and clinical trials (including a database of open trials).
- www.imtooyoungforthis.org: An invaluable source of support and research for survivors in their 20s and 30s and their families.
- www.cancersurvivorsunite.org: Camps and support programs for young adults with cancer.
- www.youngcancerspouses.org: A site designed to connect couples dealing with the ups and downs of cancer.
- www.cancerconsultants.com: Contains detailed, consumer-friendly information on the latest treatment developments.
- www.americancancersociety.com: This American Cancer Society site provides basic information, alternative therapies, ways to manage the disease, and support programs.
- www.oncolink.com: This University of Pennsylvania site offers key cancer info and pointers.
- www.cancerguide.org: A how-to on researching your disease, searching for clinical trials, and finding out about the latest traditional and alternative therapies.
- www.cancer.net: American Society of Clinical Oncology site provides oncologist-approved information to help patients make informed decisions about their health care.
- www.gildasclub.org: Named for *Saturday Night Live* comedian Gilda Radner, who died of ovarian cancer, this site provides a support network for patients and their families.
- www.thewellnesscommunity.org: The Wellness Community provides support and education for cancer patients and caretakers—and hooks them up with others going through the same thing. It provides info on local wellness communities and even offers a virtual wellness community in Spanish.

everything and everyone she met, from the physicians to the gurus to the quacks. (Beware of quick fixes, she warns: “If anyone offers guarantees—run!”)

She conducted her search for an oncologist as though she were CEO of a company that she dubbed Save My Ass Technologies, Inc., treating prospective doctors as though they were job applicants. “If it was the perfect fit: fine,” she says. “If not: next!” She nixed some of the candidates for their poor bedside manner (“There should be mutual respect”), others because of their proposed treatment plans. Among the dismissed: the one who recommended a triple organ transplant (her liver and both lungs). “Some doctors are still caught up in the old model of nuke it and cut it out—and sometimes it is really not necessary.... In my case it was not the protocol,” Carr says. “Do you want them to be stabbing at you if they’re taking that stab in the dark? It’s important to make sure you’re in the right hands. They can help you, or they can kill you. It’s that simple.”

The more physicians she interviewed, the more she came to realize that “half the time they don’t have the

“We are still

answers,” but it is the ones willing to admit that fact who hold the most promise of finding them. Enter the doctor she “hired”: George Demetri, director of the Center for Sarcoma and Bone Oncology at the Dana-Farber Cancer Institute in Boston, who, unlike many of the other “job applicants,” not only has the medical credentials but, she says, is also “kind and compassionate” and welcomes his patients’ input.

Keeping Tumors at Bay

CARR SAYS Demetri believes that she can live her “whole life” with the disease but that it may have to be treated with drugs at some point. “We don’t know. There is currently no cure,” she notes, “but there’s no doubt in my mind that any new information, drugs, and



Medical Resources

Finding a doctor who specializes in cancer care and choosing a treatment facility are essential steps in any patient's recovery program. One good place to start is with the 63 cancer centers that the National Cancer Institute recognizes for "scientific excellence and the capability to integrate a diversity of research approaches" (http://cancercenters.cancer.gov/cancer_centers). You can also check whether the American College of Surgeons' Commission on Cancer (www.facs.org/cancerprogram) approves of a given program. Some of the things to look for in a cancer center include a low mortality index, a high ratio of nurses to patients and opportunities to participate in clinical trials. For more tips, see www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility. Here is a selection of some of the most respected cancer treatment centers around the country:



Dana-Farber Cancer Institute
Boston
866-408-DFCI
www.dfci.harvard.edu

Memorial Sloan-Kettering Cancer Center
New York City
212-639-2000
www.mskcc.org

Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Baltimore
410-502-1033
www.hopkinshospital.org/health_info/Cancer/index.html

Children's Hospital of Philadelphia
215-590-1000
www.chop.edu/consumer/jsp/division/service.jsp?id=26696

Duke Comprehensive Cancer Center
Durham, N.C.
888-ASK-DUKE
www.cancer.duke.edu

University of Texas M. D. Anderson Cancer Center
Houston
877-MDA-6789
www.mdanderson.org

University of Chicago Medical Center
888-UCH-0200
www.uchospitals.edu/specialties/cancer

Mayo Clinic
Rochester, Minn.
(facilities also in Arizona and Florida)
507-284-2511
www.mayoclinic.org/cancer-treatment

University of Washington Medical Center
Seattle
206-598-4100
<http://uwmedicine.washington.edu/PatientCare/MedicalSpecialties/SpecialtyCare/UWMEDICALCENTER/Cancer>

UCLA Medical Center
Los Angeles
800-UCLA-MD1
www.uclahealth.org

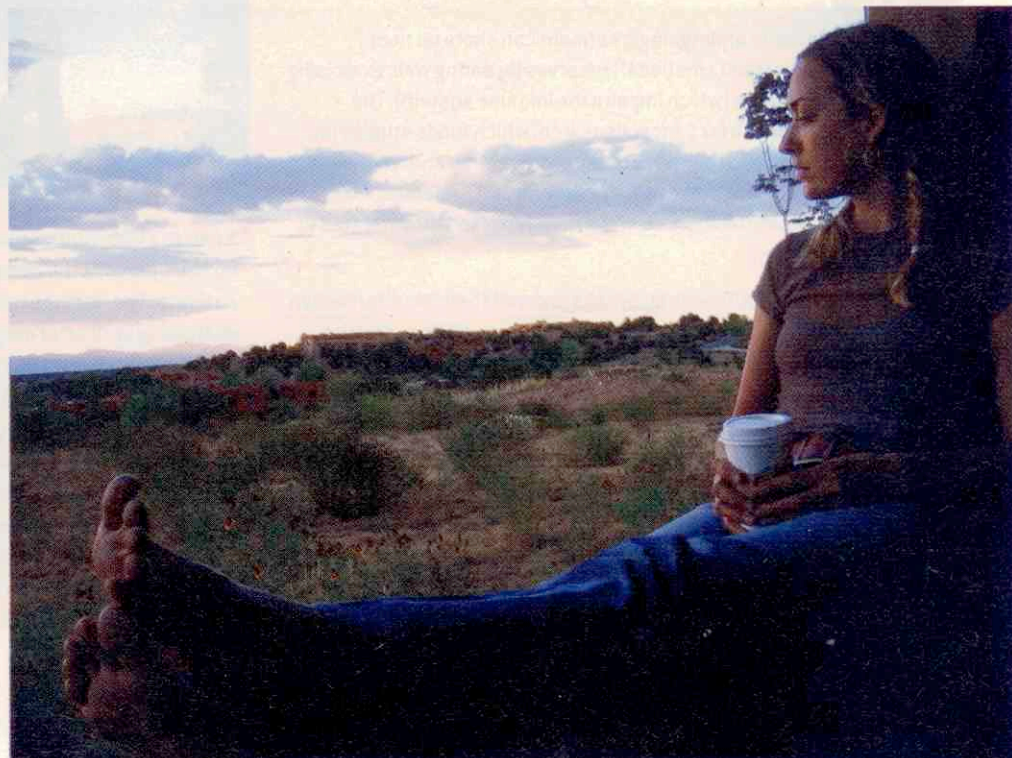
empowered. I have cancer, but I'm dealing with it."

treatment is going to come out of this place [Dana-Farber]. I'm in the right place to be monitored."

Four years after turning the camera on herself, Carr turned her healing journey into a documentary called *Crazy Sexy Cancer*, which TLC bought in the fall of 2006. Last year it had its world premiere at the South by Southwest Film Festival in Austin, Tex.

"I'm not saying that cancer is sexy," she stresses. "What I'm saying is that we are still empowered. We are still alive and whole. I might have cancer, but I'm dealing with it and I'm still all that. The most important thing is to have a voice and use it."

Carr is among a growing num-



HEINZ LINKE (Stockphoto [Job]); LISA COCCIARDI (Carr)



The 411 on Health Insurance



Worried that your health insurance won't cover your treatment? Wondering if you're entitled to disability benefits? These Web sites may help:

- www.healthinsuranceinfo.net
- www.patientadvocate.org
- www.patient.cancerconsultants.com
- http://cancerguide.org/disability.html
- www.thedisabilityexpert.com
- www.ssa.gov/applyfordisability

ber of people living and thriving with cancer, thanks to medical advances as well as a progressive philosophy in oncology that recognizes past mistakes of overtreatment and welcomes alternative medicine as a partner in the healing process. The new approach, she says, shatters the stigma that cancer is either a death sentence or something that has to be eradicated—and opens the door to treatments designed to keep tumors in check, which could buy time while new therapies are developed. “Many amazing new treatments are targeting tumors and leaving patients with their

lives and their immune systems [intact],” she says. “Plus, there is so much that we as patients can do to help our bodies regain health.”

Carr is currently developing a non-profit organization that will work with top oncologists on studies and research using data from the more than 1,000 members of her online community (www.crazysexylife.com) and the 5,000 to 10,000 people who visit her Web site (www.crazysexycancer.com)

every week. “We want to be the bridge, one of many bridges, between Western and alternative medicine,” she says.

When first diagnosed, Carr viewed cancer as a freight train to death; now she views it as a “catalyst” for change. She changed her lifestyle, met a new community of women and ditched acting for writing, something she never believed she could do. Last year she wrote and published *Crazy Sexy Cancer Tips* (Globe Pequot Press), a book chock-full of practical advice on everything from doctor shopping to diet to how to keep your wits about you when diagnosed with the Big “C” (or any other disease, for that matter). She wrote a companion book, *Crazy Sexy Cancer Survivor: More Rebellion and Fire for Your Healing Journey*, due out in September—and is set to pen a diet and lifestyle manual to be published next year.

Perhaps most important, she says, cancer led her to her “soul mate.” She recruited Brian Fassett to help her film, edit and produce her documentary. During the project, they fell in love—and Fassett and Carr (who, when first diagnosed, thought she would never date

“Once I was able to change my focus,



How to Stay Healthy

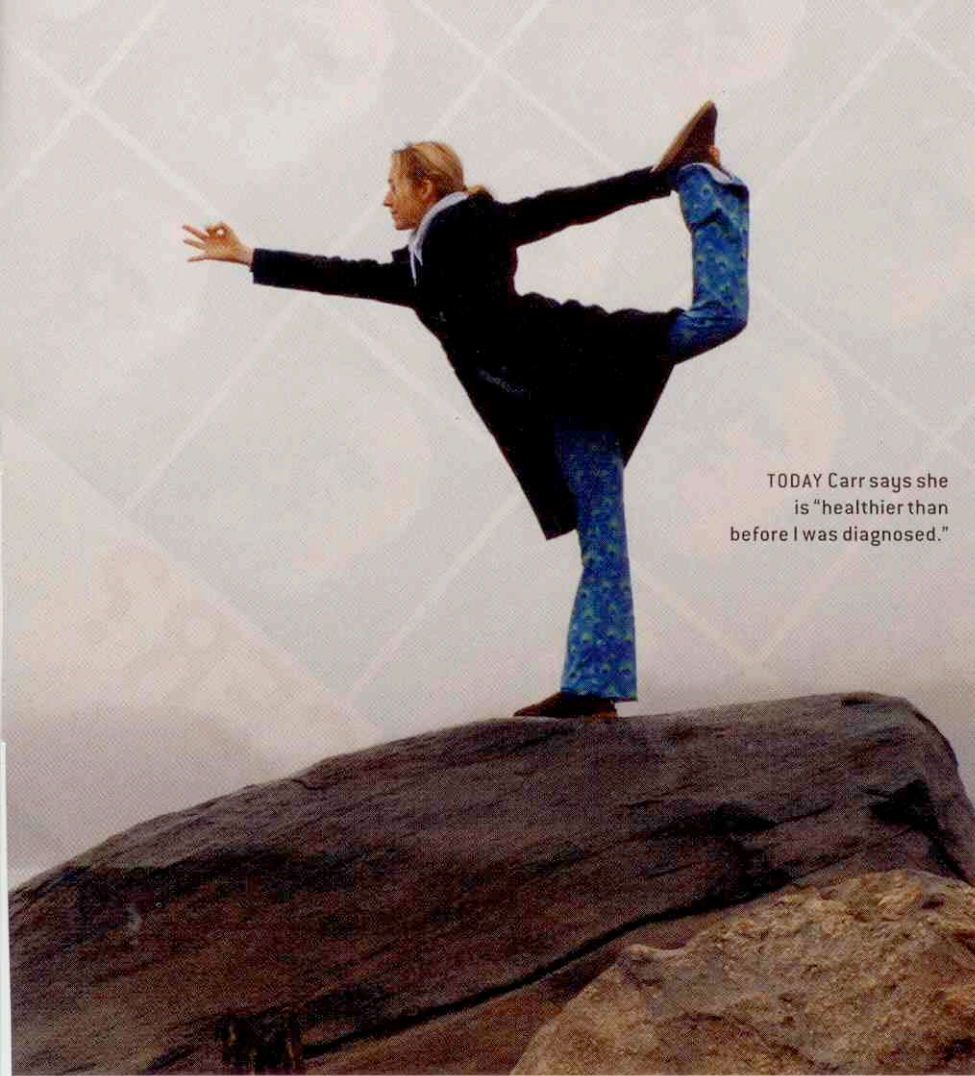
Patients undergoing treatment can shore up their physical (and emotional) reserves by eating well, exercising and cutting stress (which impairs the immune system). The American Institute for Cancer Research, which funds studies on the role of food and exercise in cancer prevention and treatment, recommends a diet that's at least two-thirds vegetables, fruit, whole grains and beans. Below is a roundup of research related to staying healthy:

■ A study of 22,000 healthy Greeks showed their “Mediterranean diet,” rich in vegetables, whole grains, olive oil, fruit and fish, reduced their risk of dying from cancer by at least 25 percent. Other studies have found that nutrients in dark, leafy greens may inhibit the growth of tumor cells in breast, skin, lung and stomach cancers and that green tea may thwart cancer development in colon, liver, breast and prostate cells. (A leading theory: flavonoids in tea and carotenoids in leafy greens, which act as antioxidants, may protect against cancer by rooting out free radicals.)



- A pair of 2006 studies showed that regular exercise reduced by up to 61 percent the odds of death in colorectal cancer patients. The findings held even in patients who did not start exercising until after diagnosis.
- A 2005 study showed that 92 percent of nearly 3,000 women with breast cancer who walked or did other exercise three to five hours weekly were still alive 10 years after their diagnosis, compared with 86 percent of those who exercised less than an hour a week.
- A 30-year review of the scientific literature, published in 2004, suggested that cancer patients who feel helpless or who suppress negative emotions may be at greater risk of having their cancer spread than those who play a role in their healing.

PAMELA MOORE (olders), JENNY HILL (runner) AND VICTOR MELNICUC (fruit) / iStockphoto



TODAY Carr says she is "healthier than before I was diagnosed."

desperation led to inspiration."

again, let alone marry) got hitched in the fall of 2006. "It was one of the happiest days of my life," she says. "We vowed to be fellow adventurers. We thought it would be way too melodramatic to say 'till death do us part.' This was a day that cancer just was not a part of." They are now considering having kids. ("Will the hormones wake the sleeping dragon? We don't know," she says, "but I refuse to live my life in fear.") And they have started their own production company, Red House Pictures.

So how is the 36-year-old Carr today, more than five years since her life-altering diagnosis? "I am happy and, I think, healthier than I was before I was diagnosed." Her last scan in February showed the tumors are stable.

Looking back on her healing journey, she muses: "The doctors told me to 'watch and wait.' What I prefer is the

'watch and live' approach. I'm not waiting, putting my life on hold. I'm living my life, just with the knowledge that cancer is in my body.

"I think that life is just too sweet to be bitter. Once I was able to change my focus, desperation led to inspiration. I made so many changes, and I thought: This is an awesome life. I mean, honestly, I don't think anyone has a better life than me. How can you live with the knowledge of cancer? I might not ever be able to get rid of it, but I can't let that ruin my life.... I think: Just go for it. Life is a terminal condition. We're all going to die. Cancer patients just have more information, but we all, in some ways, wait for permission to live." ■

Lisa Stein is news editor for Scientific American's Web site, www.SciAm.com.



Looking Ahead: Start a Family?



Does a cancer diagnosis spell the end of your dreams to have a family? In a word—no. Note to readers: check your options *before* undertaking treatments that may cause infertility. In the event that you cannot become pregnant, there is always surrogacy and adoption. Despite what you've heard, it *is* possible to adopt if you've had cancer. The key: pick an agency and country that are open to working with cancer survivors.

For more, check out:

- www.fertilehope.org: This site provides unvarnished facts about fertility risks associated with cancer treatment as well as fertility-preservation and parenthood alternatives before, during and after treatment. It outlines the success rates, costs and time requirements for a variety of fertility procedures and also addresses other possibilities, including egg and sperm donation, surrogacy and adoption.
- www.pregnantwithcancer.org: This Web site links newly pregnant cancer patients with others with a similar cancer who have already been there, done that.