



WEST COAST ASSEMBLY TO ADDRESS STIGMA

NCCS' fourth annual meeting next fall will highlight the issues of stigma in insurance, employment, and public attitudes. Conferees, who will meet from Thursday, November 16 through Sunday, November 19, will address both advocacy and research questions.

They will also participate in workshops focusing on a range of matters, from treatment decisions and health care provider burnout to self-empowerment, community action, and elderly and minority group concerns.

The Radisson Plaza Hotel in Manhattan Beach, CA, a short distance from the Los Angeles International Airport, will host the Assembly. Room rates will be at a special rate of \$65.00 a night for both single and double occupancy. Discount travel arrangements for attenders are being made through American Airlines.

With the Assembly still in the planning stages, member ideas are welcome. Contact: Chair Selma Schimmel, Vital Options, 4419 Coldwater Canyon, Studio City, CA 91604, (818) 508-5657.

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ADVOCACY UPDATE

—Barbara Hoffman, J.D.

Two Bills Would Expand Survivors' Job Rights

- A breast cancer survivor is fired from her job as a paralegal shortly after her mastectomy. She was unable to convince her employer that she lost her breast, not her brain.

- A hotel kitchen employee is transferred from his job for fear he might "contaminate" the food.

- A corporate senior executive is forced to resign, although he had demonstrated that he could perform his job while undergoing treatment for Hodgkin's disease.

I testified before a Senate Labor and Human Resources Subcommittee in February on behalf of these survivors and others of the over 1,000,000 Americans who

have experienced some form of job discrimination solely because of their cancer histories. I told the members that these things had happened although 80% of adult cancer survivors return to work successfully after diagnosis, and studies have shown that they have had relatively the same productivity rates as other workers.

Chairman Christopher Dodd (D-CT) and his colleagues wanted to know about their treatment (which includes dismissal, demotion, and loss of benefits), because he has introduced the *Family and Medical Leave Act* (S.345/H.R.770). This legislation would require employers

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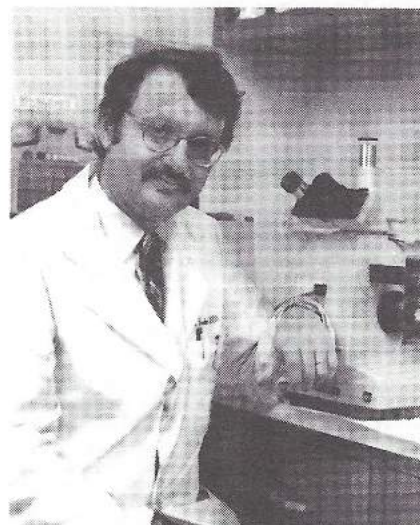
WHAT'S NEWS

NCI Happenings:

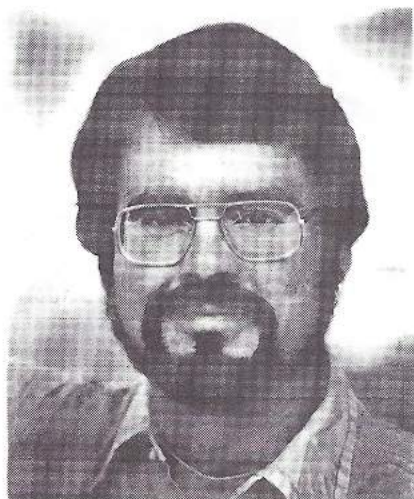
Broder on Survivorship

In response to a Networker query, Dr. Samuel Broder, the new National Cancer Institute Director said: "As a growing number of Americans survive cancer, they face a number of issues, such as rehabilitation, treatment options, psychological support, employment and insurability. NCI is committed to help meet the needs and concerns of this growing population. This is exactly the kind

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"NCI is committed to help meet the needs and concerns of this growing population..."—Dr. Samuel Broder



LETTER FROM THE PRESIDENT

Fitzhugh Mullan, M.D.

In early February I had the chance to meet with William Tipping, the new Executive Vice President of the American Cancer Society, to discuss the ACS and NCCS. Barbara Hoffman and Natalie Davis Spingarn joined us as did Irving Rimer, a former ACS vice president and an advisor to Mr. Tipping.

Bill Tipping comes to ACS from a successful career in private business, almost twenty years as an ACS volunteer, and experiences in his personal life with cancer and survivorship. In his six months on the job, he has already managed the difficult and important move of ACS headquarters from New York to Atlanta.

Bill Tipping is interested in survivorship. In his judgement, the Service and Rehabilitation side of

the ACS—the programs for patient support and education such as "I Can Cope" and "Reach to Recovery"—have not received the emphasis that he thinks they should. He plans to push rehabilitation and survivorship as priorities for the \$300 million ACS.

He knows the NCCS and sees us as a potential collaborator in this effort. We briefed him on the scope of the survivorship movement and our program of networking, membership development, publications, and conferences. We reviewed a number of possible models of cooperation including obvious items such as joint sponsorship of National Survivors Day or conferences on survivor-related topics. We also talked about other possibilities for financial or staff support for specific NCCS activities.

This was a first meeting, but an excellent one. Cooperation and collegiality were the keynotes. We plan to meet next in Atlanta to continue the dialogue.

THANK YOU

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The *Networker* is a quarterly publication of the National Coalition for Cancer Survivorship. NCCS is a network of independent organizations and individuals working in the area of cancer survivorship and support.

The primary goal of NCCS is to generate a nationwide awareness of survivorship, showing that there can be a vibrant, productive life after the diagnosis of cancer. NCCS facilitates communication between people involved with cancer survivorship, promotes peer support, serves as an information clearinghouse, advocates the interest of cancer survivors and encourages the study of survivorship.

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SUPPORT THE MEMBERSHIP DRIVE....

As NCCS grows and its programs develop, keep in mind that the effectiveness of our organization—its power and strength—depends in large part on our numbers. NCCS needs to increase the size of its membership in all parts of the country.

Will each of you join this effort by recruiting at least three new members this spring? Your help and support are needed.

—The Board of Directors

WHAT'S NEWS

(from page 1)

of problem we look forward to addressing."

Broder added that "Research into long-term survivorship and a plan of activities including a 'Survivor's Kit' are part of NCI's activities to help these survivors look to the future with courage and optimism."

Meanwhile NCI's Office of Cancer Communications (OCC) reported progress in several survivorship areas:

- Collaboration with NCCS on planning and developing the educational and informational kit for survivors and their families mentioned by Dr. Broder (preparation of the kit begins in March, 1989);

- Addition of survivorship information within the next six months to revisions of such publications as *After Breast Cancer*, *Chemotherapy and You*, *Eating Hints*, and *When Cancer Recurs*;

- Preparation beginning in January 1989 of an annotated bibliography of the cancer survivor literature. Contact: Katherine Crosson, MPH, Director OCC Patient Education Program, (301) 496-6792.

For NCI Research

A late January National Coalition for Cancer Research (NCCR) meeting in Washington focused on proposed cuts to the NCI budget, at a time when scientists feel years of work on the biology of cells appears ready to yield major payoffs. NCCR urges members (of which NCCS is one) to write to their senators and congressmen to support increased health research funding (and suggests you tell them your experience as a beneficiary of research breakthroughs.)

Assistance Available

NCCS Technical Assistance Committee Chair Betsy Wilson

calls attention to the workshops on all aspects of non-profit organization management offered in 11 cities by the nonprofit Support Centers of America. Contact: Support Centers of America, 1410 Q St. NW, Washington DC 20009, (202)462-2000.

Betsy also recommends:

- *The Self-Help Sourcebook*, which describes hundreds of mutual-help groups meeting stringent non-profit guidelines, and includes lists of clearinghouses, toll-free help lines and other resources. Order (for \$8.00) from St. Clares-Riverside Medical Center, 1 Indian Rd, Denville, NJ 07834, (201)625-9565.

- *The NonProfit Times*, free for nonprofits. Write: PO Box 870, Wantagh, NY 11793-0870.

NH Column Answers Cancer Questions

A syndicated weekly newspaper column, produced at Norris

Cotton Cancer Center (NCCC) in Hanover, NH, provides information that will encourage earlier cancer detection and treatment, and help survivors, their families and friends deal with the practical and emotional impacts of the disease. Experts at NCCC, a federally designated cancer center within the Dartmouth-Hitchcock Medical Center, review and answer the questions, drawing on outside resources as necessary.

Most of the questions sent to the column, called *Living with Cancer*, come from readers in New Hampshire and Vermont, and are guaranteed a response by letter. Letters from outside the NCCC's treatment area cannot be guaranteed a personal response, but those of general interest are answered through the column. Contact: Susan J. Scown, Editor, *Living with Cancer*, Norris Cotton Cancer Center, Hanover, NH 03756 (603)646-5544.

From sunny Florida, Cancer Survivor Brad Zebrack and his friend Joanne Kelleher reported on their year-long bike trip on behalf of NCCS and survivorship:

The odometer clicked to 6500 miles as we cycled into Columbia, SC, our gateway to "southern hospitality." After appearing on TV in Columbia and Augusta, GA, we were stopped often by people along our route who offered a meal or an on-the-spot donation.

Among the highlights:

- *Meeting Jimmy and his 7-year-old son Jason during a 5 1/2 hour, two meal visit at Taylor's BBQ in Waynesboro, GA, with a parade of friendly, curious passers-by. Jimmy shared his fears and concerns about Jason and his chemotherapy treatment, but Jason was more interested in how Santa Claus would find us on the road.*

- *Visiting and playing "Pictionary" with an enthusiastic group of teenage cancer survivors at Richland*

BikeAmerica: Rolling Along

Memorial Hospital in Columbia. This support group, called "Lasting Impressions," showed a video they have produced for newly diagnosed patients.

- *Meeting the diverse people that make up this country, from the oncology nurses in Hartford, CT to the children at Memorial Sloan-Kettering Cancer Center in New York City and the staff of Ronald McDonald House in Richmond, VA.... We've been touched by those we've touched. Thank you.*

Their schedule:

(Contact: Barbara Hoffman, [609]799-9199) New Orleans, LA (3/2/89); Dallas, TX (3/21/89); Amarillo, TX (4/6/89); Albuquerque, NM (4/19/89); Phoenix, AZ (5/8/89); Los Angeles, CA (6/4/89).

PRIVACY ALERT

Sensitive Health Information Goes to Third Parties; You Have "Bundle of Rights" to Your Medical Record

Washington attorney Robert R. Belair specializes in privacy and information law. Formerly counsel to the National Commission on Confidentiality of Health Records (NCCHR, 1976-79), he served as advisor to the National Conference of Commissioners on Uniform State Laws when it adopted a model Health Records Law. His interviewer, Networker Editor Natalie Davis Spingarn, was executive director of NCCHR.

Q. It has taken a long time for us survivors to get to the point where we can talk and deal openly about our cancer. Do you feel privacy is an issue for us as well?

A. I think so. Any patient, long term or short, needs to be concerned about privacy because health information is sensitive. In the hands of the wrong party, or even misused by the right party, health record information can result in the loss of a job, or can have an adverse effect on credit or other opportunities.

Q. Most survivors I talk to think their medical records are safe with their doctors. How can information leave the doctor's office?

A. In two ways, and they are related. First, very few people pay for their own health care any more. So you have third parties who have legitimate needs for information in order to make payment decisions. And of course physicians have an incentive to provide these payers with information so they can get paid.

Q. So health information leaves health care providers' files?

A. Routinely. It finds its way into the hands of third party payers or insurers. And they may keep infor-

mation so they can make future underwriting decisions. Plus some payers in some circumstances provide information to still other parties—consumer reporting or private investigating agencies who are in the business of making consumer reports or selling information. Computerization, of course, has made it easier both to store and retrieve information.

The second main way in which information spreads has evolved because most people get their health care paid for through their employers. So information flows to employers and they use it for employment decisions. Given several equally qualified prospective employees, employers might use some aspects of the information about cancer survivors—speculation about life span, for example—to deny them jobs.

Q. What can survivors do to assure privacy?

A. In almost every state, you can get a look at your own record. That's important, because by looking at the record, you can determine how great a risk it poses for you. The rules vary enormously; some states require institutions such as hospitals to provide access, but other states require health care professionals or government-sponsored providers to provide it. But today patients have some sort of access to their records in all but a handful of states.

Q. What if a doctor won't let you see your record?

A. There isn't a state that doesn't have lots of providers who believe in access—that access is a patient right and that it may be therapeutic. So if you live in a state that

doesn't give you access, or even in one that does and you have a physician who is reluctant to provide it, my advice is don't mess around trying to exercise your legal rights. Do it the easy way; find a physician who believes in access.

Q. What if a survivor wants to change doctors and take his or her record along? Do we own our own records?

A. The physical record itself technically belongs to the health care provider (doctors often sell their records to other practitioners when they retire or move). But the subject has a *bundle of rights* with respect to the information in the record.

Q. And that bundle of rights...?

A. Permits access to the record; limits dissemination of information in the record; assures that the information is correct and is used appropriately. Because patients have these rights, most doctors will forward the record to a successor physician.

Q. Many, many survivors have been in some sort of support therapy to help them deal with their medical problems. This is often paid for through health insurance.

A. Mental health treatment is probably the most frustrating area for privacy proponents (including psychiatrists and psychologists), because we've got this 19th-century notion that automatically turns mental health care into a black mark. And though mental health information is very sensitive, it still goes to third party payers and still finds its way to employers and those in the business of investigating people. To avoid stigma, some people pay for that kind of care out of their own pockets, and this has an adverse economic effect on both patients and providers.

Q. Does group therapy entail

special risks?

A. Yes. The doctor-patient privilege laws assume a situation where a patient provides information to the doctor in the context of a one-to-one relationship.

The trouble is that this privilege is lost if a patient discloses information to a doctor in front of other people (even, in some cases, in front of a nurse). In group therapy, it doesn't apply except in a few states (like Illinois and the District of Columbia) which have adopted mental health confidentiality statutes.

Q. So peer support groups are vulnerable?

A. They are simply not protected.

Q. What can survivor groups do to protect themselves?

A. So far as groups are concerned, the best thing is to establish an understanding right at the outset—reduce it to writing—to establish the fact that this is a confidential relationship and we agree not to divulge what's said here to any other party under any circumstances.

Q. Should survivors be assertive about their privacy?

A. Absolutely. And they should be privacy conscious—there's a lot of anecdotal evidence, for example, that a great deal of gossip goes on in medical settings and this gossip can be harmful, causing patients to lose their jobs, or their marriages, and hurting their relationships with their children.

Q. Where can people find out more about privacy questions and file complaints?

A. The best place is the health provider licensing body in your state.

If you have further questions, write Robert Ellis Smith, publisher, *Privacy Journal*, PO Box 15300, Washington, DC 20003, with a copy to the *Networker* at NCCS headquarters.

(ADVOCACY, from page 1)

that employ 20 or more workers to provide an employee who becomes seriously ill with 13 weeks of unpaid job protected leave, and the continuation of any existing health insurance coverage.

Along with another bill, the *Americans With Disabilities Act*, this legislation would send a clear signal to the nation's employers.

The Disabilities Act would prohibit those that employ 15 or more workers from discriminating against qualified workers with a disability or history of a disability. For example, if you are qualified, and not hired solely because you have had a history of cancer, the Department of Labor or a federal judge has the right to order the employer to hire you.

Your Testimony Needed...

Congressional leaders who support these bills want to hear from you. If your story shows how the new legislation would benefit you or other—including future—survivors, write a one to two page letter describing your experience (i.e. when you were diagnosed and with what, your current health, what type of job you held or sought, how you were treated at work).

If you were employed when you were treated for cancer and either were fired *because* of your diagnosis or were required to stay on the job while you were ill because you had no job security, send the letter to:

Jackie Ruff, Re: Family and

Medical Leave Act, Hart Building, Room 639, United States Senate, Washington, DC 20510.

If you were qualified for a job, yet treated differently *because* of your cancer history (denied a job, fired, denied benefits, etc.), send the letter to:

Liz Savage, Re: Americans With Disabilities Act, Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD 20785.

Another way you can help is by writing to your Congressman (U.S. House of Representatives, DC 20215) and Senators (U.S. Senate, Washington, DC 20510) to express your support. You could send them copies of the stories you send the above.

Joe Kogel

To Borrow from Each Other's Strength

...I was going to say that (ours) is not a journey for the weak—but that's precisely who it is for. It's for the weakness we all feel, for the protection and admission of that weakness. We are here to borrow from each other's strength, for strength is a natural resource we know we *must* share if the great ecosystem is to right itself. We are learning not to hoard ourselves—and discover abundance in the process. We take some of that surplus back with us, to our private ecosystems of health, home, work, and family.

... Don't get me wrong. I'm into

goals. I think you've got to map out where you want to go. I think it helps to see it all, feel it all, taste it all coming true. But if we can at the same time admit that we don't know that our goals will be reached, without diminishing our determination to reach those goals—then I think we're seeing whatever we're looking at, drinking in all the information it has for us unabashedly. We're moving together, in sync and in trust into the unknown of our choosing.

—From the closing speech of the
Third Annual Assembly,
November, 1988

PEOPLE WATCHING

Catherine Logan

NCCS' executive director, a nine-year survivor of invasive cervical cancer, lives in Albuquerque on a half-acre homesite complete with adobe walls, corral, and sweat lodge. She spends the little leisure time she has with her partner, Tino Carrillo, and enjoys caring for their garden and animals—horse, dogs, cats, and chickens.



Once a jeweler and businesswoman, Cathy founded Albuquerque's Living Through Cancer Survivorship Center. The daughter of a Presbyterian minister (whom she lost to breast cancer) from Decatur, IL, she is a co-founder of NCCS and an expert on survivor groups.

Harvey Newman

As CEO for Cancer Care, Harvey manages an organization that each year serves over 14,000 clients at three major sites in New York, New Jersey, and Long Island at a budget of over \$7 million. Before joining Cancer Care, he held executive positions at the Greater New York Fund/United Way, Community Service Society and Hamilton Madison House.



The author of the American Management Association's *Self Evaluation and Planning for Human Services Organizations*, Harvey has acted as a management and

planning consultant to many social welfare organizations. He has taught Social Welfare Management for a decade at the Hunter College School of Social Work, and now serves as NCCS treasurer and management committee chair.

Lloyd Ney

PAACT—Patient Advocates for Advanced Cancer Treatments—is the brainchild of Lloyd Ney. A retired engineer and journalist, Lloyd saw the need for an organization steering men to effective treatment for prostate cancer during his own battle against the disease.

Headquartered in Grand Rapids, MI, Lloyd and PAACT offer information on all aspects of prostate cancer, including clinical trials, updates on federal approval of new drugs, insurance issues, testing procedures, and statistics. After his own successful hormone therapy, Lloyd, 70, became a leading proponent of hormone therapies for prostate, and other cancers as well.



Ann Leach

Founder and director of the Cancer Support Network in Bloomington IL, Ann has worked as a publicist for Kansas City's Midlands Theatre. She plans to continue her interest in the arts by developing workshops in art, music, and drama



therapy for cancer patients and their families.

Ann says she is a survivor "by association," since both her parents died of cancer. She is interested in the effects of cancer on the family unit and in the development of survival techniques for family members. She was named to the NCCS Board of Directors last spring and serves as its membership chair.

SURVIVORS DAY SLATED FOR SUNDAY, APRIL 30

Cancer survivors across the country will celebrate the achievement of a full life after cancer at the second National Survivors Day April 30. This year, the event is sponsored by the American Cancer Society and COPING magazine, and endorsed by the NCCS.

As planning for the event began in January, ACS national headquarters sent out a memo to all its divisions calling attention to NCCS interest in Survivors Day and its wish to be helpful in finding speakers, and otherwise promoting the celebration.

According to NCCS Executive Director Catherine Logan, several ACS division officials have called indicating a wish to cooperate. Some members are planning their local celebrations on different dates because of weather, custom, or availability of resources. Cooperation with local ACS divisions or units in selecting an alternate date is still possible.

Former ACS Vice President for Public Relations Irving Rimer and Jennifer Camp, Executive Vice President of COPING, are coordinators of the 1989 Survivors Day. Call your local ACS division or unit for further information. A limited number of Survivors Day press kits are available from NCCS headquarters in Albuquerque.

NETWORKER READER

(from page 8)

through the informational text leaves readers feeling "in the company of others."—Catherine L. Logan

INTIMACY: Living as a Woman

After Cancer, by Jacquelyn Johnson, (NC Press Limited, Toronto, \$12.95). There are excellent sections in this creative book about the emotional experience of cancer, which does not duplicate others currently available. I would particularly recommend two

chapters: "Love Heals," for survivors with concerns about their sex lives, and "You and Your Mate," which details mate fears in a useful way. Throughout, there is important information for families—such as allowing time to grieve, and pointing out the unpredictable nature of the coping-grieving cycle.

Although INTIMACY may reassure and inform patients who are psychologically aware, its graphic and vivid emphasis on the traumatic aspects (which have

generally been understated in other books) could be upsetting for others. And there are some scattered inaccuracies and exaggerations. For instance, the comparisons about the emotional and sexual effects of breast and gynecological cancers are speculative at our current state of knowledge. It is my experience as a psychotherapist and sex therapist that problems in this area relate more to individual spouse and couple adjustment prior to cancer than to their type of cancer.—Lucy R. Waletzky, M.D.

TO HONOR SURVIVORSHIP

To honor the survivorship of those you love, we suggest a donation to NCCS. This could be made to mark recovery, a milestone such as a birthday, or to memorialize a life. In any case, a donation gives you a fine way to celebrate courage in facing the challenge of cancer.

The membership coupon below has been changed to permit you to specify information about your gift, and to whom you wish its acknowledgement to be sent.

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Annual Membership Options

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Invisible Scars: A Guide to Coping with the Emotional Impact of Breast Cancer, by Mimi Greenberg, Ph.D., (Walker & Co., \$17.95). If you have had a diagnosis of breast cancer, or know someone who has, this how-to book gives you sensible and up-to-date information. In dispassionate, light (some might say flip), prose, it helps the patient along the thorny paths of modern treatment and care—and addresses some troublesome emotional baggage, from unhappy patient-doctor relationships through getting professional help ("sooner is better") to dating.

Psychologist Greenberg, a breast cancer survivor and counselor, is upbeat, and sometimes intriguingly pragmatic: "Pair a pleasant event/activity immediately following an unpleasant one"—like a radiation or chemotherapy treatment. Or "Take his Temperature" on the first or second date, casually mention that you just visited with a friend or relative who was recently treated for breast cancer; "see what his reaction will be." Some may find all this easier said than done. Life, being unfair, often isn't that simple. But others will profit from the author's supportive approach. We would all have profited from more complete thoughtful, appendices (NCCS, for example, is not mentioned in Appendix C, Organizations of Interest)—Natalie Davis Spingarn

NETWORKER READER

TAKING CHARGE of Your Medical Fate, by Lawrence C. Horowitz, M.D., (Random House, \$18.95). It's so easy to place our fate in the hands of our doctor or surgeon; but is that the best way to insure survival? Dr. Horowitz says not; "When you are sick, whether or not you recover often depends more on which door you walk through than on what illness you have." As staff director of the U.S. Senate Subcommittee on Health from 1977 to 1981, he discovered an "astonishing variation" in medical care throughout the country. Not just a diatribe, his book is packed with solid information and recommendations.

TAKING CHARGE is about choosing the best doctor and the best hospital for surviving any major disease—and knowing when to change doctors. There is, however, a chapter on cancer that,

among other things, explains PDQ—Physician Data Query, a National Cancer Institute computerized data base. (Individuals can find out more about PDQ and what it contains by calling the NCI Cancer Information Service [CIS] at 1-800-4-CANCER.) Appendix 2 is a 75-page printout that illustrates what the system can provide (in this case, on breast cancer). For cancer survivors this could be the most valuable part of the book. The other appendices give names and telephone numbers of NIH officials and addresses of state schools of medicine.—*Ed McCartan*

I Can Cope: Staying Healthy with Cancer, by Judi Johnson, R.N., Ph.D. and Linda Klein, (DCI Publishing, \$8.98). "Information is power. Lack of knowledge regarding cancer can render the person with cancer powerless." So the

authors of this fine resource proceed to empower their readers. Written for those dealing with the acute and extended stages of cancer survival, the book is patterned after the I Can Cope educational program (co-founded by Johnson). It begins with the personal stories and cancer diagnoses of nine individuals and then covers a broad range of issues from cancer and treatment to the day-to-day psychosocial challenges: emotions, family, sexuality, stress, support systems and financial and legal problems. Practical suggestions for handling difficult situations and a chapter listing resources make this book especially valuable.

Although the book may seem insensitive to those who try unproven methods (implying they are emotionally immature and lacking in courage), most survivors will find it supportive. Weaving the nine individual experiences
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