



## Special report: the cancer bill

A bipartisan bill calling for Medicare coverage of clinical trials makes its way through the Senate. A 4-page package on the bill's provisions, why we need it, and a meeting between advocates and Senate staff.

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### Speaking up on talk radio

It's showtime. With a huge audience and an entertaining format, talk radio makes a terrific forum for cancer advocates. Here's how to prepare to make airwaves.

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## About NCCS

*The National Coalition for Cancer Survivorship, a nonprofit organization, addresses the needs and interests of people with cancer, their families, healthcare professionals, and cancer organizations. Our core mission is to provide information and referral resources on the physiological, psychological, economic, and social impacts of cancer.*

*NCCS—the only national organization founded of, by, and for individuals with all types of cancer—advocates on issues affecting survivors at the national, state, and local levels. Since our founding in 1986, NCCS has recognized the importance of providing a voice for people who have been diagnosed with cancer.*

*Our philosophy of "the veteran helping the rookie" is intrinsic to our belief that the wisdom of a person's experience can contribute to responsible advocacy based on that experience. The dramatic growth of the survivorship movement over the past 10 years offers a vivid affirmation of that premise.*

*If you would like more information about NCCS, you can request a general information packet by calling 301/650-8868.*

## FOR MORE INFORMATION



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NCCS internet home page: <http://www.access.digex.net/~mkragen/cansearch.html>



## ADA protections: not a sure thing

BY DANIEL FIDUCCIA &  
BARBARA HOFFMAN, JD

While federal laws now protect cancer survivors' employment rights, the way courts interpret those laws has yielded a mixed bag in recent rulings.

Some cancer survivors face a Catch-22 under employment discrimination laws. If they are too ill to work, courts may consider them "unqualified" for protection under the law because they cannot perform the essential functions of their jobs. If they can work during or after cancer treatment, courts may refuse to recognize their disease as a "disability."

Some courts have ruled in favor of cancer survivors, as in the case of Keith Cline. Two weeks after he was promoted to night-shift supervisor at a Wal-Mart in Virginia, Cline was diagnosed with a recurring brain tumor. Wal-Mart approved his medical leave and assured him he would not lose his job.

But two days after he returned to work, the new store manager demoted him—and then fired him after he complained. The court awarded Cline \$300,000—the maximum allowed under the Americans with Disabilities Act (ADA).

Unfortunately, other courts have limited survivors' rights under the ADA. In a recent case, a federal court reversed a favorable verdict for a malignant-lymphoma survivor in Jacksonville, FL.

Returning to work from a three-week medical leave, repairman Mervin Gordon was fired after a dispute with his supervisor. Gordon had worked throughout chemotherapy treatment and despite suffering side effects such as weakness, loss of hair, and vomiting.

The court ruled he was not a "qualified individual with a disability" under the ADA. Since the survivor missed only 10 days of work for treatment, the 11th circuit reasoned, he was fully capable of working and therefore his cancer did not "substantially limit his ability to care for himself or to work."

As this decision shows, misconceptions

about cancer persist. Some rulings view cancer as an always-disabling diagnosis, while others consider some cancers temporary and relatively minor medical problems.

Thus cancer survivors need to become their own best advocates on employment issues. How? Learn the basics of the laws. Know how and when to file a proper request for medical leave or reasonable accommodation with an employer. Make sure you know and meet the deadline for filing a complaint if you suspect discrimination. Providing accurate medical and work records to your attorney can help you avoid litigation or present a strong case if you pursue a lawsuit.

The NCCS publication, *Working It Out: Your Employment Rights as a Cancer Survivor*, summarizes your rights and outlines strategies you can use to protect them.

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*Some rulings view cancer as an always-disabling diagnosis, while others consider some cancers temporary and relatively minor medical problems*

This summer, NCCS will publish *Cancer On Trial*, a report aimed at advocates who represent survivors in cases involving employment and insurance disputes. It highlights current federal court decisions affecting survivors' rights under the ADA and other federal laws, and lists resources and articles that may help support a survivor's claim. (See story, page 16.) ♦

*Daniel Fiduccia, a former board member of NCCS, is a disability-rights advocate. Barbara Hoffman, NCCS general counsel, is editor of A Cancer Survivor's Almanac: Charting Your Journey.*





## Lawmakers seek to untangle Medicare mess

BY THERESA LAUERHASS &  
TERRENCE CAMPBELL

**T**True or false: Medicare reimburses cancer patients for care received in clinical trials. Answer: True *and* false. Sometimes it does and sometimes it doesn't. A bill now circulating in the Senate aims to end that contradiction—and the mayhem it causes in the lives of countless cancer survivors.

Democrat Jay Rockefeller (WV) and Republican Connie Mack (FL) have teamed up to propose the Medicare Cancer Clinical Trials Coverage Act (S. 381). The act would ensure that Medicare beneficiaries with cancer could receive treatment in clinical trials without fearing Medicare would deny reimbursement.

Says Sen. Rockefeller: "Our legislation is an effort to give Medicare beneficiaries the security and decency of knowing that if they are diagnosed with cancer, their treatment options will be determined by whatever therapy they and their doctor decide will give them the best shot of beating the disease.

"These life-and-death decisions should not be guided by what may or may not be paid for by the Medicare program."

The bill, commonly known as the Rockefeller-Mack bill, shows strong promise of gaining wide bipartisan support. Rockefeller and Mack have already recruited 23 other senators from both parties as co-sponsors of the act.

The measure would establish a demonstration project requiring Medicare to cover routine patient-care costs for beneficiaries enrolled in high-quality cancer clinical trials.

The four-year project requires the Secretary of Health and Human Services to submit a report to Congress detailing cost and other benefits by January 1, 2002. Congress would review the results and decide whether to enact permanent legislation.

### Do they or don't they?

Currently, Medicare policy on reimbursement for care received in clinical trials is unclear and inconsistent. Medicare regulations state that the program must pay for "usual patient care" costs for patients treated in a research setting.

### About clinical trials

To develop new and more effective treatments for cancer, scientists start in the laboratory with basic research and animal studies. A promising treatment progresses to the next stage, clinical trials—studies conducted with volunteer cancer patients.

Some clinical trials test a treatment in one group of people. Others compare treatments in separate groups of people who share certain similarities such as type or extent of disease.

The researchers publish their results for review by other medical experts. Such regular reviews help to establish the safety and effectiveness of a treatment plan.

Individuals enrolled in clinical trials receive state-of-the-art care. Their care is closely monitored and they receive either the best existing therapy or a new therapy that shows promise of being even more effective.

For detailed information on clinical trials, request a copy of "What Are Clinical Trials All About?" from the Cancer Information Service (800/4-CANCER) at the National Cancer Institute. The booklet describes types of clinical trials, what it's like to participate, things to consider before enrolling, and much more.

—Terrence Campbell



Despite this provision, officials of the Health Care Financing Administration (the federal agency that oversees the Medicare and Medicaid programs) say that any care received in a clinical trial is "experimental" and therefore not covered by Medicare.

These conflicting positions foster arbitrary and uncertain reimbursement practices. In reality, Medicare carriers often do pay for usual patient care costs for individuals with cancer treated in peer-reviewed clinical trials.

However, in other instances, Medicare refuses to cover similar care solely because it is provided in a trial. Some patients and their doctors appeal these denials. Time-consuming appeals strain the patient's energy and resources, making a painful situation even worse.

Not knowing whether Medicare will cover care given in a clinical trial, many beneficiaries with cancer hesitate to participate in one—even if it offers the best chance of recovery. Physicians, too, think twice before enrolling a Medicare beneficiary in a trial, fearing coverage denials and the burdensome appeals process.

Allen Lichter, MD, president-elect of the American Society of Clinical Oncology, stressed this point during a recent Senate briefing. "We're making steady progress in the fight against cancer," he said, "but intermittent and arbitrary denials of coverage for clinical trials may discourage both physicians and patients from participating in the research effort, which would be a tragic setback."

### What about the cost?

The bill would limit Medicare's coverage to:

- only the highest-quality clinical trials, including those meeting standards set by the National Cancer Institute, the Food and Drug Administration, the Department of Defense, and the Department of Veterans Affairs.
- only routine patient-care costs—such as physician and hospital fees and routine diagnostic tests. The program currently pays for such care when provided outside a trial setting. Thus the bill would merely ensure that Medicare fulfills its already-existing responsibility to beneficiaries for whom the best treatment option is a clinical trial.

The Rockefeller-Mack bill does not require Medicare to pay for research costs. Those costs—including any additional data collection or testing required under a research treatment plan—would still be covered by a trial's sponsor, such as the National Cancer Institute or a pharmaceutical firm. Pharmaceutical companies would also continue to pick up the tab for new drugs or other agents under study.

### Saving lives and money

At a time when the Medicare budget faces tough scrutiny, supporters of the Rockefeller-Mack bill contend the legislation will actually reduce expenditures.

How? Only through clinical trials can researchers determine which therapies work

## Good as gold

Although the Rockefeller-Mack proposal would affect only Medicare coverage for cancer clinical trials, cancer survivors outside of Medicare have plenty of reasons to support it. The bill's passage would likely cause a ripple effect reaching well beyond the Medicare system.

As the nation's largest third-party payer, Medicare's reimbursement policies often serve as a model for private insurers' coverage decisions.

Such was the case in 1993 when Congress enacted legislation requiring Medicare to cover certain self-administered and off-label anticancer drugs. Private insurers generally followed this lead by adding coverage for similar drugs to their policies.

As a result, many people with cancer have gained access to improved anti-cancer therapies.

As the baby boomer generation ages, many will likely be eligible for Medicare coverage in the not-too-distant future. As survivors live longer, long-term and late effects can take their toll—a compelling reason to support the bill.

The measure would significantly reduce pain and suffering for the population most affected by cancer: the elderly. This population accounts for over 50 percent of cancers diagnosed—and 60 percent of all deaths. Thus the bill would ensure coverage for state-of-the-art medical care for the people who most need it.

Plus, by advancing valuable clinical research and establishing clinical trials as the standard of care, the Rockefeller-Mack proposal would expedite research discoveries that will save and extend lives, and improve the quality of life for millions of Americans diagnosed with cancer in coming years.

With so many points in its favor, the Rockefeller-Mack Medicare clinical trials coverage bill holds great promise for major progress in improving the quality of care people with cancer receive. It clearly deserves the full support of everyone with cancer and those who support them.—*Sam Turner*





and which do not. Clinical trials also help determine which therapies are most cost-effective. Without a robust clinical trials network, new potentially costly treatments may become widely available before they are proven effective.

Critics of clinical trials coverage (primarily third-party payers) argue that costly new treatments, such as autologous bone marrow transplants, make reimbursement for care in trials too expensive.

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*"We're making steady progress in the fight against cancer, but intermittent and arbitrary denials of coverage for clinical trials may discourage both physicians and patients from participating in the research effort, which would be a tragic setback"*

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But such treatments are the exception, not the rule. Only about 3 percent of adults diagnosed with cancer participate in clinical trials. And the Congressional Budget Office recently reported the costs of patient care in and out of trial settings as roughly equal.

In fact, many new treatments offered in trials cost far less than standard therapy. Jane Reese-Coulbourne, executive vice president of the National Breast Cancer Coalition, received just such a therapy when she participated in a trial of the National Cancer Institute.

### **Please help**

You can help make this legislation a reality. Write to your state's senators. Tell them you support S. 381, the Medicare Cancer Clinical Trials Coverage Act. Ask them to sign on as co-sponsors and to encourage similar legislation in the House of Representatives. Ask friends, family members, or members of your support group to write letters, too. Do it today!

The care she received successfully treated her stage III breast cancer—at one-tenth the cost of the standard care she would have received had she not enrolled in the trial.

"It makes no sense for an insurer to refuse to cover this care," she says, "when it would otherwise pay for a less effective therapy costing 10 times as much money."

### **A boost to research**

Beyond the cost savings, clinical trials advance cancer research. That translates into extended life and improved quality of life for millions of Americans diagnosed with cancer.

Investments in clinical research have already yielded significant achievements in cancer treatment. According to Seth Rudnick, MD: "There have been impressive advances in the treatment of leukemia and Hodgkin's disease in the last 30 years, and that progress can be traced directly to the clinical trials that tested investigational therapies for those diseases." Dr. Rudnick is a board member of the Leukemia Society of America.

### **Senate support growing**

The cancer community overwhelmingly supports the Rockefeller-Mack proposal. Among the bill's champions: NCCS, the Cancer Leadership Council, the American Cancer Society, the Oncology Nursing Society, the American Society of Clinical Oncology, the American Association for Cancer Research, and the Association of Community Cancer Centers.

This resounding endorsement is already making an impact in the Senate. However, given Congress' full agenda, cancer advocates cannot afford to assume the bill will pass.

Individual cancer survivors and grassroots groups must make their voices heard on the critical need for this legislation. Without it, Medicare coverage of clinical trials will continue as a game of heads-or-tails—with cancer survivors' lives and fortunes hanging in the balance. ♦

*Theresa Lauerhass is an associate at the law firm of Fox, Bennett & Turner in Washington, DC. Terrence Campbell is editor of the Networker.*



# Advocates boost proposal at Senate meeting

BY DONNA DONESKI &  
THERESA LAUERHASS

The menu featured baked chicken. But at a Senate luncheon briefing in February, the diners had more on their minds than poultry. They had gathered to discuss a bill that holds profound implications for cancer survivors.

Sen. Jay Rockefeller (D-WV) and Sen. Connie Mack (R-FL), joined with cancer advocates to tell Senate staffers about the pivotal role clinical trials play in treating people with cancer. Their goal: to gain support for the senators' legislation requiring Medicare to pay for treatment received by beneficiaries in clinical trials.

"For many cancer patients, the best available care is offered in clinical trials," declared Ellen Stovall, executive director of NCCS.

"Unfortunately, the reimbursement policies of Medicare and other third-party payers discourage patients from enrolling in clinical trials."

Stovall called clinical-trials coverage a consumer-rights issue: "Medicare beneficiaries who have paid their premiums and taxes over the years have a right to expect that the program will be there for them when they need it most—when cancer strikes."

Said Senator Mack: "Researchers have identified noncoverage by Medicare and private insurers as one of the primary reasons why patients do not participate in clinical trials." He added: "Clinical trials are one of the most effective ways the federal government has of determining which treatments are most effective."

Rockefeller announced that he and Sen. Mack had received a letter from three Nobel Prize laureates in medicine endorsing the legislation.

Signed by Michael Brown, MD; Alfred Gilman, MD, PhD; and Joseph Goldstein, MD—the letter said, in part: "For people with cancer, clinical trials represent the standard of care and are often the best hope for a successful treatment outcome. Only by supporting

clinical research will we be able to advance the state of medical knowledge and learn more quickly which medical interventions are effective and which are not."

Sen. Rockefeller acknowledged that persuading a cost-cutting Congress to pass the bill could prove tricky. But he insisted that the act would generate minimal, if any, costs.

"This bill does not create a new benefit," he said. "It merely ensures that patients enrolled in clinical studies receive Medicare coverage for the same type of routine patient care costs—such as hospital and physician fees—that would be covered outside of a trial setting."

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*"Medicare beneficiaries have a right to expect that the program will be there for them when they need it most—when cancer strikes"*

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Whether the Senate staffers were swayed by the advocates' appeal remains to be seen. Still, 23 senators have signed on as co-sponsors at press time—a high number for a bill in its early stages.

The Leukemia Society of America sponsored the meeting, along with the Cancer Leadership Council (CLC) and the American Society of Clinical Oncology (ASCO). The CLC is an informal coalition of major cancer groups spearheaded by NCCS. ♦

*Donna Doneski serves NCCS as assistant to the director. Theresa Lauerhass is an associate at the law firm Fox, Bennett & Turner in Washington, DC.*

# The new health insurance law: what it means to you

BY KIMBERLY CALDER, MPS

If you or someone in your family is a cancer survivor, you may have had problems getting health insurance, or staying insured when your job or other circumstances changed. Many small businesses have likewise been barred from purchasing insurance for their workers if just one of them had a history of cancer or other illness.

*Generally, the new law will affect people who receive health insurance from their employer, either as beneficiaries of employer-operated plans or members of a group policy purchased from an insurance company*

A new federal law, the Health Insurance Portability and Accountability Act (also known as the Kennedy-Kassebaum act after its leading sponsors, Senators Edward Kennedy and Nancy Kassebaum), will make it much easier for most people to get and keep health insurance. Although Congress passed the bill last August, most of the law's provisions take effect July 1, 1997.

Generally, the new law will affect people who receive health insurance from their employer, either as beneficiaries of employer-operated plans or members of a group policy purchased from an insurance company.

Unfortunately, the law only covers persons enrolled in, or eligible for, one of these forms of group coverage. People who buy an insurance policy for themselves and their families—typically those who have left a job to become self-employed—make up the “individual” market. The new law does relatively

little to address the need for reform of this market, but it does establish strong inducements and timeframes for state legislatures to do so.

## Denials denied

The Kennedy-Kassebaum act will prevent group health plans from denying coverage to any legitimate applicants (including their dependents) because of past or present health problems or claims history. And insurers cannot reject anyone for coverage because of their genetic makeup—a key provision for cancer survivors and people genetically at risk for cancer.

Newborns or newly adopted children with medical problems cannot be kept out of the group either, provided the parent enrolls the child within 30 days of birth or adoption, and the child's condition is covered. Plus, cancer survivors or others with a medical history cannot be singled out to pay a higher premium than anyone else in the group.

## An end to job-lock

Congress understood that cancer survivors and many others were afraid to change jobs for fear of losing their coverage altogether, or of losing coverage for a pre-existing condition. The new law addresses the latter problem by assuring that when you change from one group plan to another, even your pre-existing condition will be covered after 12 months of continuous coverage. (Pre-existing conditions are those for which medical advice, diagnosis, or treatment was received or recommended within the previous six months.)

## MEMO

If you are considering a job change, remember: the protections described in this article are not yet in force. They go into effect July 1, 1997.



Even if you are becoming insured for the first time in your life, your pre-existing condition cannot be excluded from coverage for more than one year. And expenses for other healthcare needs that occur during your pre-existing exclusion period will be covered in the meantime.

Here's an example of how you can change from one group policy to another, even with a cancer diagnosis:

Bill is a 28-year-old survivor of Hodgkin's disease. He has worked for his current employer for nine months and received group health insurance benefits during that time. He receives a better job offer in another city.

He takes the job and enrolls in the new group plan right away. His new insurance plan will not cover his cancer costs for the first three months, but will cover expenses for any other medical care he needs during that time. After the third month, Bill's cancer-related costs will also be covered because at that point he will have been continuously insured for 12 months.

#### **Insurance-related tax incentives**

In a controversial move, the new law will allow a limited number of people who are self-employed or work for small businesses to receive certain tax advantages if they set up a medical savings account, with health insurance provided through a high-deductible policy.

The premiums for long-term care policies will become tax deductible, as will certain other costs related to long-term care not covered by insurance. The law will allow for penalty-free withdrawals from individual retirement accounts (IRAs) for medical expenses that exceed 7.5% of adjusted gross income.

#### **The shortfalls**

Although the Kennedy-Kassebaum act will help make health insurance more accessible, it does little to make it more affordable. Thus it will not significantly improve the circumstances of millions of Americans who don't have insurance because they cannot afford it.

Another major shortcoming: insurers will still be able to exclude coverage for specific conditions and impose lifetime limits, or "caps," on benefits if they so choose. And, as previously noted, more reforms are needed to assure those who buy their own insurance access to the coverage they and their families need.

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*Although the Kennedy-Kassebaum act will help make health insurance more accessible, it does little to make it more affordable. Thus it will not significantly improve the circumstances of millions of Americans who don't have insurance because they cannot afford it*

Health insurance can be very confusing and tricky to deal with when you make changes for any reason, such as taking a new job or enrolling in Medicare. Be a wise consumer: check out the details and implications of any changes you make well in advance. For more information about health insurance, consult NCCS' new *A Cancer Survivor's Almanac: Charting Your Journey*. ♦

*Kim Calder is co-author (with Irene Card) of "Straight Talk about Insurance and Health Plans," a chapter in the new NCCS Almanac. She serves as associate executive director of the National Alliance of Breast Cancer Organizations.*



# Speaking up on talk radio

BY TERRENCE CAMPBELL

*The following is based on a workshop at the Health Action '97 conference in Washington, DC, in January. It also draws on "Making Radio Work for You," a report published by Families USA Foundation. Special thanks to Greg Marchildon, Families USA press secretary, who led the workshop.*



Cancer advocates today can choose from a brave new world of communication tools to get their message across. But good old-fashioned talk radio remains one of the most potent.

Talk radio now enjoys a massive, and faithful, following. One in five American adults listen to talk radio at least twice a week. The hosts, from Larry King and Rush Limbaugh to local celebrities, attract listeners with their colorful personalities and controversial subjects.

Listeners form a bond with talk-show hosts that television personalities envy. Usually the fans agree with the host's opinionated views. Call-in formats allow for a kind of democracy in action in which regular folks can have their say.

Talk radio is not straight news. Instead it offers a rough-and-tumble mix of news and entertainment. Stations and hosts give entertainment value highest priority to hold their share of audience and advertising. Advocates can fit

into this scheme well by projecting their views in a spirited and upbeat style.

## Look before you leap

Before you try to book a spot on a talk show, ask yourself these questions:

- Is your issue timely? If your organization has just released a new study on rising healthcare costs, that's newsworthy. But your organization's stance on a bill that passed two weeks ago won't get you on the air.
- Is your topic controversial? A hot subject draws more listeners and makes you an attractive guest.
- Can you explain your subject in a few sentences? If your topic is complex or you speak like a policy wonk, you will put the listeners to sleep.
- Will the listeners likely agree with your position? If not, the backlash could hurt your organization's reputation.

If you decide to try to get a radio booking, you need to take several steps.

Select a spokesperson who knows the subject and knows how to communicate it with punch and poise. Decide which shows to target, keeping in mind the host's bias.

Polish your message. Rehearse it with your spokesperson. Have colleagues roleplay callers to the show.

Send a persuasive, upbeat letter to the shows you've chosen. Keep it short, simple,

## About Families USA

Families USA Foundation, a national nonprofit organization, advocates for "affordable health and long-term care for all America's families." The group engages in public education, policy research, organizing at state and local levels, and advocacy. Families USA publishes *Health Care Choices*, a series of books "designed to help consumers find their way through America's health-care maze."



and colorful. After you fax or mail the letter, follow up with a call to the host or producer. Try to book them on the spot.

### It's showtime

Once you're on the air, keep these pointers in mind:

- Remember what the host wants—namely, a lively, entertaining program. Project enthusiasm and show you're not afraid of a debate.
- Use the host's name. Say something like, "Hi, Rush. It's a pleasure to be with you today." Most of the audience likes the host. How you treat him or her will influence their view of you.
- Don't let the host or a caller rile you. Stay calm, don't get defensive, and focus on your message.
- Play "broken record." Make a message triangle—three main message points—and repeat them three times every fifteen minutes. People tune in and out of programs. Repeating yourself ensures that you get the message across.
- If the conversation veers off track, bring it back to your message. And if the host misrepresents your views, say so—firmly but not defensively.
- Remember the audience. Help them follow your argument by keeping it clear, simple, and in context.

### To learn more

Families USA has published "Making Radio Work for You," an advocate's guide on how to use radio to voice your organization's views. Offers detailed instructions on working with both news radio and radio talk shows. Cost: \$20. Write: Families USA Foundation, 1334 G St NW, Washington, DC 20005.

### For media advice

Families USA has effectively incorporated talk radio into its advocacy work for years.

They can provide expert advice to help other organizations do the same. For guidance on radio or any other media strategy, call their media department at 202/628-3030.

- Put a face on the issue. You can say "budget cuts in Medicare will hurt older Americans." But saying "my mother can barely make ends meet and simply can't afford to pay more for medical care" conveys the same idea with more power.

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*With a little training and practice, you can add radio talk shows to your organization's communication plan. There's an audience out there that wants to hear your message, and you can get it to them by surfing the radio airwaves*

- Go easy on the statistics. Pick one or two that support your message and make sure they're accurate. Avoid percentages. Many people find them difficult. Instead of 10%, say one in 10, as in: "Americans spend one out of 10 dollars of their family budgets on healthcare."
- End on a high note. Thank the host and restate your message.

With a little training and practice, you can add radio talk shows to your organization's communication plan. There's an audience out there that wants to hear your message, and you can get it to them by surfing the radio airwaves. ♦



# Choosing the right peer-support program

BY CATHERINE LOGAN-CARRILLO

*The following article is excerpted from "Reaching Out: The Power of Peer Support," in NCCS' A Cancer Survivor's Almanac: Charting Your Journey.*

**Y**ou are the only one who knows what is best for you. Different kinds of peer support are appropriate for different people, or even for one person at different times in his or her survivorship. Do some careful thinking and researching before you decide when and where to go for peer support. Your decisions should be based on your own values and beliefs, as well as on your physical and financial situation. Think about your experience with giving and receiving support in previous difficult situations. Trust what your experience tells you about your own style of seeking help; at the same time, do not be afraid to try something new.

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*Trust what your experience tells you about your own style of seeking help; at the same time, do not be afraid to try something new*

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If available, you may want to look for a group that focuses on your particular kind of cancer, especially if you have a more common diagnosis like breast cancer or prostate cancer; or, you might decide to attend a group that includes people with all kinds of cancer, one that includes survivors and family members, or perhaps a specialty group, like one for long-term survivors or young adults.

Consider your own personal needs over everything else. Are you looking for emotional support to relieve feelings of isolation and fear,

or are you hoping to find information and strategies for dealing with the medical system and the decision-making process? Are you looking for the inspiration of meeting others in your situation who are coping well? Whatever your reasons for seeking support, remember that your needs may change, and allow yourself to respond to that change.

If you decide to try a peer-support group, call ahead, if possible, to talk with the group's contact person. You can also ask to speak with group members and ask for print material with a description or history of the group. Some groups list only a time and location for meetings, in which case you will have to save questions until you meet someone from the group.

You may want to ask the group's contact person the following questions:

- How many people attend the group's meeting and what is the make-up of the group (survivors, family members, age range, kind and stage of cancer diagnoses, etc.)?
- How long is each meeting?
- Is the group limited to a certain frequency or number of meetings?
- Does the group have an established core of members who generally attend meetings?
- How long has the group been meeting?
- Who leads the group session and what is his or her experience or training?
- Do group leaders have a personal experience with cancer?
- What is the format of the group meetings?
- Is the primary focus sharing feelings and experiences or sharing information?
- Are there any group guidelines or ground rules?
- What kinds of subjects are discussed? Are there any subjects that are off-limits?
- Are group members asked to share a particular philosophy or approach to cancer?

These questions have no right or wrong answers. But the responses should give you a feeling for whether the group is for you and



whether its leaders are thoughtful about providing a quality group that is responsive to group members' needs.

### Have you found the right group?

When you first try out a cancer support group, look for the following:

- The atmosphere is welcoming to newcomers.
- The group's process encourages constructive solutions and does not dwell only on problems.
- Group members participate actively in supporting each other and do not look to the group leader as the expert.
- The group has a sense of shared ownership; one or two members do not dominate the group process.

Remember, groups have different personalities. Not everyone is a good match for every group, no matter how well a group functions. Does the group feel comfortable to you? Trust your own instincts, but give a new group a second and third try, unless you are absolutely sure it is not for you. One or two meetings may not be enough to get the feel of a group. If you decide the group is not for you, check out another group, if possible. It may be a better fit. When you find the right group, it should feel a little like coming home. ♦

*Cancer survivor Catherine Logan-Carrillo, a cofounder of NCCS, is executive director of People Living Through Cancer, a New Mexico support network based in Albuquerque.*

## Where to look

No single source will have information about all of the peer-support resources available to you. For this reason, it is probably wise to inquire about support resources for more than one of the following places:

- Social service departments or discharge planners at local hospitals or treatment centers
- National organizations like
  - NCCS at 301/650-8868 (Maryland)
  - Cancer Care, Inc. at 800/813-HOPE
  - The National Alliance of Breast Cancer Organizations at 800/719-9154 (New York)
  - Us Too International (for prostate cancer groups) at 800/808-7866 (Illinois)
  - Candlelighters Childhood Cancer Foundation at 800/366-2223 (Washington, DC)
- Cancer Information Service of the National Cancer Institute at 800/4-CANCER
- American Cancer Society at 800/227-2345
- State self-help clearing houses
- Yellow pages of the telephone directory under "social service organizations" or "support groups" or the white pages under "cancer"
- Psychologists, counselors, social workers, or clergy
- Newspaper listings of support groups and help-lines
- Reference libraries
- Public health offices and mental health associations

—from NCCS' A Cancer Survivor's Almanac: Charting Your Journey.

## GET YOUR COPY

This article is just a sample of the wealth of information you will find in NCCS' *A Cancer Survivor's Almanac: Charting Your Journey*. See the insert for more information, and order your copy today!



## Lymphedema: A nurse's search for answers

BY SONJA TYLER

**T**he first time Saskia Thiadens, RN, encountered a case of lymphedema, she had never even heard of it. Back in the early '80s, a woman with a severely swollen arm had come to Thiadens' post-operative treatment center in California.

Thiadens was so alarmed at the woman's condition that she called a surgeon. His ho-hum response—this is normal, it'll go away—did not satisfy her. She spoke to other medical professionals and waded into the medical literature—to no avail. No one seemed to know anything about the condition.

No one in America, that is. During a visit to relatives in the Netherlands, Thiadens found, to her astonishment, that Dutch doctors knew all about the condition, called lymphedema. What's more, they had been treating it for decades.

Armed with new knowledge and training, Thiadens returned to the US, where lymphedema affects 2 million people. Lymphedema is swelling in the arms or legs caused by buildup of lymph fluid. Some people with cancer develop it following surgery and radiation, particularly if lymph nodes were removed.

"In working with patients, I realized that there were many people with this condition

and there was a major need for educating people about lymphedema," says Thiadens. To address that need, she founded the National Lymphedema Network (NLN) in 1988.

NLN provides education, emotional support, and referrals to people with lymphedema, healthcare professionals, and the general public. The group gives information on preventing lymphedema and managing its effects. The NLN also supports research into causes and possible treatments.

The group's quarterly newsletter features educational articles, a resource guide, support groups, a PenPals/NetPals section, and news on conferences and professional training courses. The NLN's website offers additional information ([www.hooked.net/~lymphnet](http://www.hooked.net/~lymphnet)).

Last September, the NLN's bi-annual conference drew over 400 healthcare professionals and patients from all over the world. The third National Lymphedema Network conference is scheduled for Sept. 17–20, 1998.

"There's a dire need to educate the medical community about lymphedema," says Thiadens. She may be about to take a significant step in that direction: Thanks to her, Sen. Edward Kennedy (D-MA) has included lymphedema in a bill calling for reimbursement for breast reconstructive surgery.

For more information on the National Lymphedema Network, call 800/541-3259. ♦

## Mothers and daughters, standing together against breast cancer

**C**harmayne Dierker can't forget the day her grown daughter was diagnosed with breast cancer.

"I felt so devastated," she says. "I thought that it should be me, not her."

Her mother's turmoil prompted Lillie Shockney to search for groups providing emotional support to mothers of daughters with breast cancer. After finding that no such

groups existed, Shockney and Dierker decided to meet the need themselves. Together they founded Mothers Supporting Daughters with Breast Cancer (MSDBC) in 1995.

The nonprofit organization's mission is to "assist mothers of daughters with breast cancer to be able to provide the optimum amount of support needed for themselves and in turn for their daughters so that they can jointly cope



with the effects breast cancer has on each of them as women, and as mother and daughter.”

MSDBC seeks to accomplish four major goals:

- to provide medical and treatment information about breast cancer
- to form local, regional, and national communication networks linking mothers and daughters with other such pairs
- to publish a newsletter reporting on breast cancer research, innovative treatments, and educational programs
- to participate in local, regional, and national efforts to increase breast-cancer awareness and promote prevention

The group has published handbooks that give guidance on how a mother and daughter can support each other through the emotional storm of a cancer diagnosis.

The mother's handbook describes ways she can provide emotional, physical, and financial

support to her daughter. The daughter's handbook features an introduction by Lillie Shockney and offers related information from the daughter's perspective.

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## *The mother's handbook describes ways she can provide emotional, physical, and financial support to her daughter*

Shockney teamed up with artist Elizabeth Halsey to create a pink-ribbon pin—the group's logo. Two butterflies adorn the ribbon, representing mother and daughter and the transformation they experience through breast cancer.

For more information about Mothers Supporting Daughters with Breast Cancer, call 410/778-1982. Or write: MSDBC, c/o Charmayne Dierker, 2710 Bayshore Road, Chestertown, MD 21620. ♦

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## Confronting an awesome—and private—challenge

**I**n a society that virtually worships physical beauty, people with facial disfigurements confront an awesome challenge.

Just ask Betsy Wilson. She lost her jaw and palate to cancer 25 years ago. She knows firsthand the kind of resources it takes to rebound from such an experience.

Fortunately for others struggling with this challenge, Wilson today serves as director of Let's Face It, an organization devoted to informing and supporting people with facial disfigurements.

“Facial disfigurement is such a private experience,” says Wilson, “that many people feel a need to connect with others in similar situations.”

Regardless of the causes—such as automobile accidents, birth defects, or cancer, among many—facial disfigurements create a profound impact affecting not only the individual but family, friends, and other loved ones as well.

To help address their needs, Let's Face It offers a variety of tools. The international net-

work offers support via telephone consultations and home and hospital visits. Taking an individual, peer-to-peer approach, Let's Face It encourages those with facial disfigurements to share experiences, strengths, and hopes. The organization also educates healthcare professionals on the lifelong needs of people with facial disfigurements.

Let's Face It had its beginnings in England. Christine Piff, who lost her eye and palate to cancer, founded the service in 1986. Networks operate today in Scotland, Ireland, Germany, and India.

Let's Face It publishes an annual resource guide that catalogs organizations, resources for young adults, pain treatment, related Internet sites, and more.

Day by day, week after week, Wilson's work at Let's Face It adds up to an ongoing quest to, as she puts it, “encourage the public to value the person behind every face.”

To reach Let's Face It, call 360/676-7325. ♦

Sonja Tyler is an information specialist at NCCS.



## NCCS launches *Cancer on Trial*

It's no secret that legal research can eat up time and money. This summer NCCS will introduce a new publication that will help advocates, attorneys, and their clients save on both.

*Cancer on Trial* will feature capsule reports on court cases and decisions involving cancer-based discrimination. Attorneys and advocates for cancer survivors will find it a valuable resource in preparing for court action.

"Legal research can cost clients thousands of dollars," says Barbara Hoffman, JD, general counsel for NCCS. "Through Cancer On Trial, we hope to save advocates and cancer survivors time and resources by letting them know how courts have handled cancer discrimination cases."

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*"Through Cancer On Trial, we hope to save advocates and cancer survivors time and resources by letting them know how courts have handled cancer discrimination cases"*

Hoffman is co-editor, with Daniel Fiduccia, of the new title. Hoffman is editor of NCCS' *A Cancer Survivor's Almanac: Charting Your Journey*. Fiduccia, a former NCCS board member, is a disability-rights advocate based in Cupertino, CA.

Fiduccia notes another purpose of the publication: "We hope this will be a great service to attorneys, advocates, and government officials to educate them about discrimination against cancer survivors."

"There's information out there," adds Hoffman. "We're trying to make it easy to find."

To receive a copy, send a check or money order for \$10, payable to NCCS. Address: 1010 Wayne Ave, Suite 505, Silver Spring, MD 20910. ♦

## Stovall appointed to national policy panel

The National Academy of Sciences has appointed NCCS Executive Director Ellen L. Stovall to the newly formed National Cancer Policy Board.

The board was assembled by the National Academy of Sciences at the request of Richard Klausner, MD, director of the National Cancer Institute. The academy's National Research Council and Institute of Medicine approved the panel's formation last July.

Stovall is one of two panel member representing a cancer advocacy group. She is a 25-year survivor of Hodgkin's disease. Other board members include distinguished cancer researchers and care providers.

The National Cancer Policy Board provides a forum in which cancer community leaders can explore cancer issues of broad national interest. One major goal: to find ways to integrate cancer research findings at all levels of society.

Dr. Klausner describes the panel as "a roof under which all of us can gather to deal with issues," such as standards of care, cancer control policy issues, insurance and privacy issues, payment for clinical trials, informational and educational needs, and more.

Stovall also serves on the National Cancer Advisory Board, an appointment made by President Clinton.

Peter Howley, MD, chairs the board. Dr. Howley is professor of comparative pathology at Harvard Medical School. Joseph Simone, MD, serves as vice-chair. He is the senior clinical director of the Huntsman Cancer Institute at the University of Utah. ♦

## NCCS Town Hall hits cyberspace

Marshall Kragen was absorbed in the discussion at an NCCS Town Hall meeting when the idea hit him: "There's no reason why we can't get everybody in the world online to do this."

So Kragen, a cancer survivor and volunteer Internet liaison for NCCS, made arrangements last winter with America Online (AOL) to establish ongoing NCCS Town Halls via an Internet mailing list. AOL provides the service to NCCS free as part of its "Give Back to the



Net" program. By January Kragen had it up and running.

The electronic Town Hall meeting is not a chat-room with conversations taking place in real time. It works like this: Every month NCCS President Betsy Clark formulates and posts via e-mail a question for discussion. She sometimes includes some background material to stimulate thinking.

Every subscriber receives the posting, as well as responses from other subscribers as they arrive. The subscriber can send a comment back—usually to the whole group, although you can also communicate with another individual.

The online Town Hall opened with a discussion on "Words that Heal, Words that Harm," inspired by an NCCS survey of the same title. Respondents shared stories on most and least helpful remarks made to them following diagnosis. "We got a ton of responses to that one," says Kragen. Subsequent online meetings explored quality cancer care and cancer's effect on the family.

This program marks NCCS' first foray into electronic media. It provides survivors and supporters another way to communicate their

needs and ideas to the coalition.

By the same token, the service enables NCCS to maintain and strengthen its ties to the grassroots, and to stay current on the issues affecting survivors.

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*This program marks NCCS' first foray into electronic media. It provides survivors and supporters another way to communicate their needs and ideas to the coalition*

"We hope this will add to our further understanding of the needs of survivors across the nation," says Clark.

To subscribe, call up [listserv@listserv.aol.com](mailto:listserv@listserv.aol.com), type "subscribe nccs" (without the quotation marks) followed by your e-mail address and your name. Or contact Marshall Kragen at [mkragen@access.digex.net](mailto:mkragen@access.digex.net). ♦

## Help wanted

### NCCS has three staff positions available:

**Development associate**—works closely with executive director and board of directors to ensure consistent funding. Develops and writes grant proposals, handles membership maintenance and development, develops and cultivates fundraising database, and develops ideas for special events.

**Information technology and communications specialist**—develops and oversees NCCS online communications. Communicates online with consumer-focused audience and supports, maintains, and assists staff with internal technology and electronic communications systems.

**Managing editor**—for NCCS *Networker*. Works with editor and NCCS staff to plan issues, assigns stories, ensures fulfillment of deadlines, and writes and edits articles. Requires thorough understanding of survivorship issues and familiarity with the cancer community. Please send three writing samples.

### To apply, mail or fax a cover letter with resume and salary history to:

Judie Blanchard, Director of Operations  
NCCS  
1010 Wayne Avenue, Suite 505  
Silver Spring, MD 20912



## New Ribbon of Hope kits



New NCCS Ribbon of Hope™ kits will be available by the middle of May, in time for survivors' day celebrations and other survivorship events throughout the year.

The Ribbon has fostered a sense of spirited unity among people with cancer all across the nation. So far, the Ribbon bears the signatures of tens of thousands of cancer survivors. Many national leaders—such as President and Mrs. Clinton, Elizabeth Dole, Gen. H. Norman Schwarzkopf, and others—have signed the symbol of hope as well.

When fully assembled, the Ribbon sections form a large, radiant sun. NCCS plans to reconstruct the full Ribbon next year in Washington, DC. The kit includes:

- section of the Ribbon  
(holds about 200 signatures)
- gold pen for signing the Ribbon
- Ribbon of Hope™ display poster
- 100 flyers about the Ribbon
- 10 official roster sheets
- certificate of participation
- preaddressed padded envelope
- complete instructions on hosting the event

Cost for this improved, expanded kit: \$29.95. The charge helps NCCS meet expenses for materials, labor, and shipping and handling.

Organizers can also order gold pins sporting the Ribbon of Hope™ logo. They cost \$30 for a set of 25 pins, and add a nice touch to the occasion.

*To order kits or pins, call NCCS at 301/650-8868. Or send check or money order to NCCS, 1010 Wayne Ave, Suite 505, Silver Spring, MD 20910.*

## Mikulski submits bill to protect mammogram standards

Sen. Barbara Mikulski (D-MD) has introduced to the Senate a bill that would reauthorize the Mammography Quality Standards Act.

The act, passed in 1992, required mammography facilities to meet national quality

## Corrections

The Winter 1996 *Networker* contained these errors:

The cover caption described Harold Varmus, MD, as the director of the National Cancer Institute. Dr. Varmus has his hands full with his real job: director of the National Institutes of Health.

The caption for the bottom left photo on page 10 wrongly identified the woman as Linda Klein. In fact, she is Cheryl Kimball, Chronimed's director of publishing.

The back-cover photo caption said Neil Cantor is on the left. He's not. He's the one wearing the medal on the right.

The *Networker* editor hates errors, and regrets these.

*The act, passed in 1992, required mammography facilities to meet national quality standards. It safeguarded accurate readings and proper performance of the procedure*



standards. It safeguarded accurate readings and proper performance of the procedure.

Mammography remains the most widely available screening technique for early detection of breast cancer. Early detection dramatically improves a woman's chances of surviving the disease.

Many women live in fear that they, like so many of their friends or relatives, may develop breast cancer at some point in their lives. These women should not have to fear for the quality of their mammograms as well.

NCCS has urged Congress to erase such anxieties and address this urgent healthcare need by reauthorizing the Mammography Quality Standards Act as soon as possible. ♦

### **Cancer researchers need volunteers**

The National Cancer Institute (NCI) seeks 75,000 healthy men and women between ages 55-74 to join a cancer-prevention study.

The study will help NCI determine whether rigorous use of cancer screening tests can prevent deaths from certain cancers. The study sites are in Denver, Honolulu, Detroit, Minneapolis, St. Louis, Brooklyn, Pittsburgh, Salt Lake City, Washington, DC, and Marshfield, WI.

Previous studies have shown that medical tests can detect tumors of the prostate, lung, colon, and ovaries before symptoms appear. The current study will examine whether early detection and treatment can reduce the chance of dying from these diseases. Together they account for half of all new diagnoses and half of all cancer deaths every year.

If interested in participating in the study, call NCI's Cancer Information Service at 800/4-CANCER. Ask how to contact the nearest PLCO trial center. NCI's website offers more information at <http://www.dcpn.nci.nih.gov/PLCO>. ♦

### **Cancer-fatigue effects serious, survey shows**

A nationwide survey of cancer survivors, oncologists, and caregivers shows cancer

fatigue has profound effects, interfering with survivors' ability to work, meet family needs, and cope with the disease.

According to the survey, almost two-thirds (61%) of people with cancer say that fatigue adversely affects their ability to work. Slightly more than half (51%) say they are unable to do their usual activities because of fatigue.

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*Cancer fatigue makes just getting out of bed difficult for 29%. Another 24% are too exhausted to even eat*

Fatigue makes just getting out of bed difficult for 29%. Another 24% are too exhausted to even eat.

The survey was conducted by the research firm Wirthlin Worldwide for the Fatigue Coalition, a group of medical professionals, researchers, and survivor-advocates. Harvard, Stanford, Memorial Sloan-Kettering, the University of Chicago, and NCCS all have representatives in the group.

The survey of 419 people with cancer, released in February, confirms what cancer survivors have long known.

"Fatigue disrupts family and work schedules, negatively affects personal relationships, creates a sense of helplessness, and can lead to severe depression for many patients," says Susan Scherr, NCCS director of community relations and a member of the Fatigue Coalition.

Cancer fatigue usually results from chemotherapy or radiation treatments. Symptoms include excessive tiredness, weariness, weakness, exhaustion, and lack of energy.

The Fatigue Coalition plans a series of educational and research initiatives designed to help cancer survivors and physicians better understand fatigue and ways to alleviate it. ♦

### **NEXT ISSUE**

**A special report on cancer fatigue**



### Listening to life

*Kitchen Table Wisdom: Stories that Heal*, by Rachel Naomi Remen. New York: Riverhead Books. 336pp, \$22.95.

REVIEWED BY ARTHUR W. FRANK

Rachel Naomi Remen speaks to us in three voices: as a physician, as an ill person, and as a counselor of the ill, particularly of persons with cancer. Rachel, as everyone calls her, was born in Manhattan to parents whose shortcomings, about which she can be explicit, were exceeded only by the generosity of their love, which she inherited. Her grandfather was an orthodox rabbi who carried in his pocket mystical Judaic texts that he had brought from Russia, "written out by hand in Hebrew on very thin paper." Her aunts and uncles seem all to have been nurses and physicians. She grew up between the spiritual and the scientific, between her grandfather who valued questions and her parents' generation who valued answers.

*Can I believe in myself enough to claim all my parts and thus become healed? Do I really want that? Rachel would never pose these questions in so confrontational a way. Instead she invites you to rest awhile at her kitchen table, and in listening to her stories, listen to your own*

Rachel's world of young adulthood was similarly divided between her medical studies and her own sickness with Crohn's disease. Each condition engendered its respective loneliness, and this book is about the transcendence of loneliness. Stories join us to others even as they take us back to ourselves. Rachel's

stories can look very simple indeed, as parables look. *Kitchen Table Wisdom* shows how much wisdom it takes to be so direct, so pure in one's expression of experience, so unassuming in one's love.

Rachel tells stories about being an adolescent with Crohn's and then a young woman with an ileostomy, and what kind of care began to heal her. She tells of being offered the promotion she had sought at Stanford Medical School but how she resigned instead, realizing that she was losing parts of herself that she valued. She does not tell us about cofounding the Commonweal Cancer Help Program in Bolinas, CA, although it was on Bill Moyers' *Healing and the Mind* TV series that I, and thousands of others, first went to Bolinas and met Rachel. The poetry written at Commonweal by people with cancer, by nurses and physicians in their training programs, and by Rachel herself is available in another of Rachel's books, *Wounded Healers* (Wounded Healer Press, PO Box 273, Bolinas, CA 94924).

Rachel is always telling us about healing, integration, and our power as human beings. Rather than exhorting the reader about the effects of the mind on the body, Rachel allows us to share epiphanies of her life and the lives of those she has worked with: moments when the powers of mind and spirit were suddenly there. Her subtitle is the only immodest line in the book, but its claim is true: these stories can heal, if we can let ourselves believe. Rachel's gift as a therapist is to help people—many of whom are dying and have been variously failed by other medical and support systems—believe in themselves and in life. Her book offers us all this gift of belief.

Can I believe in myself enough to claim all my parts and thus become healed? Do I really want that? Rachel would never pose these questions in so confrontational a way. Instead she invites you to rest awhile at her kitchen table, and in listening to her stories, listen to your own. ♦

*Arthur Frank received the 1996 Natalie Davis Spingarn Writer's Award from NCCS for his book, At the Will of the Body.*



## ON VIDEO

### What do we tell the kids?

*Talking About Your Cancer: A Parent's Guide to Helping Children Cope.* Fox Chase Cancer Center. 18 mins, \$29.95 plus \$5 shipping and handling. To order, call 215/728-2668. Or write: Fox Chase Cancer Center, Dept of Social Work Services, 7701 Burholme Av, Philadelphia, PA 19111.

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REVIEWED BY WENDY S. HARPHAM, MD

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For parents, a cancer diagnosis unleashes the greatest fear of all—"What about my children?"—and presents a daunting challenge: raising normal, healthy children in the context of a parent's life-threatening disease. How can moms and dads guide their children through the crisis of a new diagnosis when they themselves are physically and emotionally compromised and often lacking in practical information about the disease and treatment? Even when parents understand what is happening medically, instincts drive them to try to protect their children from the terrible truth.

Fox Chase Cancer Center has developed a superb 18-minute video, *Talking About Your Cancer: A Parent's Guide to Helping Cope* that shows parents how to break the news and take those first painful steps toward surviving as a family. Short dramatization sequences by professional actors are artfully meshed between advice given by former Surgeon General C. Everett Koop, MD, and that of real-life mothers, fathers, and children who have been there.

The video opens with two parents who are uncertain how to tell their young daughter the shocking news. The little girl, off by herself on the staircase, voices her questions and concerns. The scene brings home the message that children are trying to figure out what is going on whether the adults say anything or not.

The guidelines offered by Dr. Koop are simple and sound, such as "Tell the children soon" and "Be honest." Information and advice are reinforced through summary screens and dialogue. A young boy's explanation of how the truth helped him deal with the reality of his mom's illness convinces those who are doubtful of the value of honesty and open communication.

The film gives enough advice without overwhelming parents: include the children, encourage open communication, be aware of the children's tendency to believe in magical thinking or blame themselves, and get help. Words of encouragement come from authorities, such as Dr. Koop, and from family members who are living the challenge. What emerges is a philosophy that can provide mooring for families who are feeling awash in changing circumstances and uncertainty: we love each other, and that is never going to change.

*Talking About Your Cancer* is an invaluable resource for parents with cancer, and for all oncology offices, treatment centers, and support group lending libraries.

Cancer survivor Wendy Harpham's new book, *When a Parent Has Cancer: A Guide to Caring for Your Children* (Harper Collins), includes a companion book for children, *Becky and the Worry Cup*.





*Retreats for cancer survivors*—Wellspring Cancer Help Program offers five-day retreats in Thetford, VT. Program allows participants to nurture and replenish themselves and explore their relationship to cancer in a safe and supportive environment. Participants also learn a wide array of techniques for promoting health and well-being. Cost: \$1,500 (includes room, meals, all program offerings). Retreats scheduled for May, June, August, September, and November. For details: 603/795-2144.

*Ovarian cancer journal*—*Ovarian Plus International*, a quarterly journal, publishes articles on prevention, early detection, international research, psychosocial issues, and cancer politics. For medical professionals and public alike. \$TK for sample issue; \$50 for one year. Mail check to Ovarian Plus, PO Box 498, Paauilo, HI 96776-0498.

*In Spanish*—The Bay Area Breast Cancer Resource Guide is now available in Spanish. The guide includes comprehensive listings of mammography clinics, hospitals, hospices in

the San Francisco area. Plus national, regional, and community action organizations. Free. Call 415/775-5921.

*En Español*—Ahora disponible en Español es la Guía de Recursos para la lucha contra el Cáncer del Seno del Área de la Bahía. La guía incluye un listado comprensivo de las clínicas para mamografías, hospitales, y hospicios en el área de San Francisco. Además organizaciones de acción a nivel nacional, regional y en la comunidad. Gratis. Llame 415/775-5921.

*Healthcare activists*—Universal Health Care Action Network (UHCAN) is a nonprofit nationwide network of individuals and organizations dedicated to healthcare for all. Its mission: "to create nationwide momentum for healthcare justice by serving to activate, unite, and strengthen local grassroots activists. Achieving justice in healthcare is part of a continuing effort to renew democracy and assure economic security" for all Americans. Write: UHCAN, 2800 Euclid, Suite 520, Cleveland, OH 44115-2418. Or call: 800/634-4442.

## MEETINGS

*Postgraduate psychosocial courses*—The dept. of social work at Memorial Sloan-Kettering Cancer Center presents "Postgraduate Institute in Psychosocial Oncology." Among the courses: cancer survivorship, psychosocial oncology in the ambulatory setting, gender aspects in cancer care, innovations in psychosocial oncology, and more. For further information, contact Linda Sibilia, Administrator Coordinator, Dept. of Social Work, at 212/639-7020.

*"Facing Forward After Cancer: Surviving or Thriving?"*—Third annual psychosocial conference of the Center for Cancer Treatment and Research, Nov. 7, 1997, in Columbia, SC. Topics: sex and prostate cancer, spirituality, rehabilitation. Panel of survivors will share their experiences. \$75. Contact Sue Heiney at 800/775-2287.

*State Cancer Pain Initiatives*—8th national meeting: "Broadening the Base, Focusing the Mission." June 26-29, 1997, St. Paul, MN. For everyone interested in eliminating barriers to cancer pain nationwide. NCCS' Ellen Stovall is a featured speaker. \$275. For more information, call Sarah Aslakson at 608/263-2856.



## SURVIVOR-LINK

### Seeking contact with someone with the same diagnosis:

*Blanch Cane*, 15712 Sahler, Omaha, NE 68116. Ovarian cancer, stage 3.

*Trudy Smith*, 91 Cozy Lake Rd, Oak Ridge, NJ 07438. Aggressive breast cancer; finished with chemotherapy.

*Leslie Reardon*, 5798 Lyman Dr, Battle Creek, MI 49017. Recurrent breast cancer.

*Marc Brueland*, 11022 Promesa Dr, San Diego, CA 92124. Phone: 619/278-9334. E-mail: BruelandEandG@webtv.net. Age 23. Rare liver cancer (fibrolamellar hepatoma).

**Neuroblastoma**—A new brochure answers key questions about this rare cancer diagnosed mostly in children, including: What are the signs and symptoms? What causes it? What tests and procedures are required? How can it be treated? And more. Send \$10 to Association of Pediatric Oncology Nurses (APON), 4700 W Lake Ave, Glenview, IL 60025-1485; or call 847/375-4727. APON also publishes a family education resource catalog listing resources available to children with cancer (\$10) and other publications.

**Cancer facts in Canada**—The Canadian Cancer Society provides accurate, up-to-date information on a wide range of topics through its Cancer Information Service. Includes details on cancer treatment, dealing with side effects, emotional and financial support, nutrition, and help in your local community. Call 888/939-3333, 9am-6pm, from anywhere in Canada.

**New brain-tumor website**—The National Brain Tumor Foundation (NBTF) has launched a worldwide website to provide information to people with brain tumors, their families, and health professionals. Explores tumor types, treatment, rehabilitation, conferences, and more. Features a story about a long-term brain tumor survivor. Location: <http://www.braintumor.org>. E-mail address: NBTF@braintumor.org. For details, call 800/934-CURE.

**Tollfree info on the law**—The US Dept. of Labor recently opened a tollfree telephone service to inform the public about the Family and Medical Leave Act. Call 800/959-FMLA.

**"Advocacy: The Cornerstone of Cancer Survivorship"**—article by NCCS' Ellen L. Stovall and Elizabeth J. Clark, PhD. Appeared in *Cancer Practice* (Sept-Oct 1996). Explores the idea of cancer survivorship as a process rather than a stage. With sections on empowering the cancer survivor, communication skills training, problem-solving skills training, the advocacy continuum, and more. Single reprint free from NCCS, 1010 Wayne Ave, Suite 505, Silver Spring, MD 20910; 301/650-8868.

**VHL handbook**—"What You Need to Know about VHL" presents information about von Hippel-Lindau disease for patients, their families, and caregivers. Covers VHL in specific organs, treatment, coping, family support, research, questions to ask your doctor, and more. Write to VHL Family Alliance, 171 Clinton Rd, Brookline, MA 02146. Or call 800/767-4845.

## MEMO

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## IN A WORD

**"Cancer sucks."**

—*lapel pins worn by scampy survivors at the Albuquerque Assembly last fall*

## NOTABLE QUOTABLES

### **"Death is no enemy"**

The ultimate value of illness is that it teaches us the value of being alive; this is why the ill are not just charity cases, but a presence to be valued. Illness and, ultimately, death remind us of living. "The way we look to a distant constellation/that's dying in the corner of the sky," Paul Simon sang. We look like a flicker of light. In the moment of that light going out, we learn that what counts is to keep it burning. Death is no enemy of life; it restores our sense of the value of living. Illness restores the sense of proportion that is lost when we take life for granted. To learn about value and proportion we need to honor illness, and ultimately to honor death.

—*From At the Will of the Body by Arthur W. Frank*

### **Beyond sympathy**

We all speak the same language; we experience a similar type of birth and a similar exposure to death. So there is bound to always be some link, some continuity between you and the other. It is something more than just mechanically saying, "Yes, I know; it hurts very badly." Rather than just sympathizing with the patient, it is important to actually feel her pain and share her anxiety. You can then say "Yes, I feel that pain" in a different way. To relate with total openness means that you are completely captured by someone's problem. There may be a sense of not knowing quite how to handle it and just having to do your best, but even such clumsiness is an enormously generous statement.

—*from The Heart of the Buddha by Chogyam Trungpa Rinpoche*

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