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**GUIDE TO  
COMPREHENSIVE  
CANCER CARE**

**PATIENT / FAMILY  
RESOURCE CENTER**

**SELF CARE GUIDES**

**TESTS & PROCEDURES**

**COMPLEMENTARY /  
ALTERNATIVE CARE**

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## *In the Know*

### Connecting Patient / Family Library Patrons To Information, Ideas and Resources

May 2005

from

**The Duke Patient/Family Resource Center**

The Duke Patient/Family Resource Center is:

- A lending library offering books, audio and video tapes, magazines and free brochures dealing with cancer and certain blood disorders and with issues of coping, survivorship, caregiving, and grieving
- Open 8:30 to 5:00 every day the Morris Clinics are open
- Located in the White Zone, first floor, of the Morris Cancer Clinic, Room 15123.
- Our phone number is 919-684-6955. Our email address is [FamilyLibrary@mc.duke.edu](mailto:FamilyLibrary@mc.duke.edu)



**Resource Center Coordinator:** [Harriet Whitehead, PhD](#)

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### Recent additions to our collection

## Reviews and News

This month, our issue is devoted to three recently added books in our collection and several breaking news items. "Hope," "coping," and "fighting" are the key issues addressed in the passages that follow.

### Reviews:

*The Anatomy of Hope*, by Jerome Groopman

Hope is the elevated feeling we experience when we see - in the mind's eye - a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. (xiv)

Dr. Jerome Groopman's now familiar formula, a series of case studies grouped around a theme, scores another stunning success with this book. As the title suggests, the theme here is "hope," that ineffable spiritual dimension that enters into every cancer patient's ability to engage the struggle with a life-threatening disease. Hope figures importantly into the doctor-patient relationship as well. Does hope have curative power? Does its absence therefore undermine the treatment? If so, are doctors then warranted in holding out hope for cure or remission at all costs, even when the facts are signaling that cure or remission is unrealistic? What is to be gained by conveying discouraging information? Or lost by withholding it? These are the issues of the book.

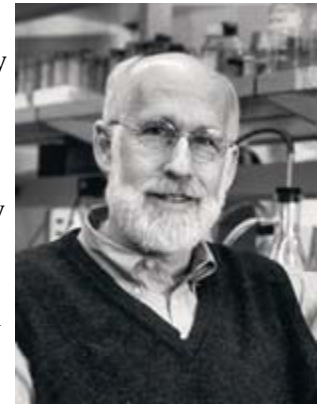
One of the more intriguing chapters in the book is the one entitled "Unprepared." Groopman recounts his own experience as a young doctor groping his way toward the proper balance between encouragement of the patient and truthfulness about the disease. In revealing examples, he will describe the patient's medical situation, then take us inside the room with patient and doctor (the doctor is sometimes himself, sometimes a more seasoned practitioner whom the young Groopman was assisting) where we

hear how the doctor explained it to the patient. Oh my! Some of these examples make us wince to read them, but they are familiar. There are doctors out there who still haven't learned the art of striking that delicate balance. Many, like Groopman in his groping days, swing between "venturing too far and too fast in the direction of cold facts," or "retreating behind a wall of false hope." Both extremes can backfire badly.

The reason the balance is a such a tricky one emerges in the chapters that follow, each centered around a particular patient. It becomes clear that patient's are extremely variable in their ability to deal with their situation. A one-size-fits-all solution to the question of what the doctor should say is ruled out. One patient who was coddled along with unadulterated optimism, died embittered when thing turn out badly, as she might have been clued they would. Another, after being told a grim statistic, was unable to enjoy her one substantial remission for thinking of how soon it might end. When Groopman tries to be upbeat with one of his early mentors, now stricken with a deadly cancer, the older doctor cuts him short with, "Jerry, I know the game you're playing. I've played it all my professional life."

The sense that the doctor can't win for losing builds, but Groopman, who is obviously a naturally upbeat guy, won't give up. And perhaps that is his secret - communicating an underlying will to his patients, a will that says he has not given up, despite what might appear in some cases to be very long odds. He writes

Each disease is uncertain in its outcome, and within that uncertainty, we find real hope, because a tumor does not always read the textbook, and a treatment can have an unexpectedly dramatic impact. This is the great paradox of true hope: Because nothing is absolutely determined, there is not only reason to fear, but also reason to hope. And so we must find ways to bridle fear and give greater rein to hope.(210-211)



A very heartening book.

Another very heartening book is



*Finding the "Can" in Cancer: A Practical Guide*, by Nancy Emerson, Pam Leight, Susan Moonan, and Terri Schinazi

The four faces that shine from the back cover of this book (left to right: Susan, Pam, Terri, and Nancy) will be familiar to many patients and staff of the Morris Cancer Clinics here at Duke. These four survivors, who collectively have represented 70 years of experience in living with cancer, have worked for or helped to build the Duke Cancer Patient Support Program, or worked with the Comprehensive Cancer Center to raise funds for cancer research. These four then went on to collaborate on a practical guide to living with cancer.

The book was self-published and could have used the services of a copy editor. You'll find typos. But have patience, it's a gem. Many of the usual topics are covered - communicating with your doctor(s), telling the kids, coping with side effects, helping others to help you - but in an unusually candid way. The different personalities will often intrude into the discussion (in italics) as individual commentators, with their own personal take on an issue. Brand names are dropped unapologetically, if one of them has a favorite remedy for a side effect. The level of detail on side effects is especially rich and personal. And you are made aware both at the beginning of the book and in subsequent places thereafter that these women, three out of the four at least, have lived for a long time with very advanced cancers. (Two of them, Nancy and Susan, died before the book was quite finished.) The effect is quite intimate, as if you were sharing the living room with four good-humored, wise and earnest life-coaches. The hope they have to offer in abundance is the hope, not of cure, but of living a rich and rewarding life even as a sword hangs over the head. They write:

It is important that you not only survive this experience but learn to thrive - not so much in spite of it, but as a result of it. It is not a life path that you would have chosen, but it is one that can enrich your life beyond measure. (220)

You may have encountered similar sentiments in other books on cancer journeys, but seldom will they hit home so convincingly as in this "practical guide."

Our library has two copies of this book for check-out, and it is available at the Duke Cancer Patient Support Program office for a donation of your choosing. Call 919-684-4497 for details. You may also order it online (for around \$10) at either of two websites:

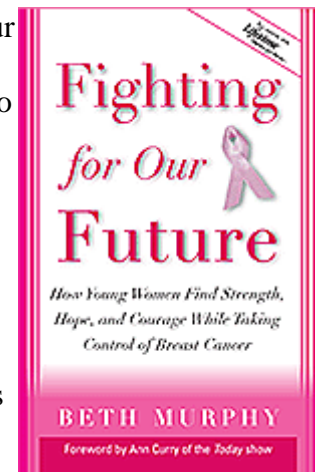
[www.lulu.com](http://www.lulu.com)

[www.wingsforacure.org](http://www.wingsforacure.org)

*Fighting for Our Future*, by Beth Murphy

Someone dropped this book off as a donation to our library - thank you, anonymous donor! - and I found it such a high level of excellence I decided to review it here.

This is a book specifically oriented toward young women with breast cancer. It's about time. Each year 10,000 women below the age of 40 are diagnosed. Just the other day a beautiful young woman walked into our Resource Center, looking for breast cancer information - for herself. She was 21 years old. It happens.



The introduction of Murphy's book says it all when it comes to the differences between younger and older women facing this cancer.

The young woman with breast cancer must deal with issues such as fertility and pregnancy, effects of therapy on sexuality, and the onset of premature menopause and its consequences. She is more likely to have an inherited predisposition for breast cancer, and must face the prospect that she may have passed a breast cancer gene on to her children. She is faced with cancers that frequently act differently, and more aggressively, than those she might have faced had she developed a breast cancer two decades later. By virtue of her age, she is likely to be at a different and more vulnerable point in career development. Her children are younger and demand more of her than she may be able to give because of the physical and emotional effects of therapy. She must face difficult body image issues, and the reality of her own mortality, all the time surrounded by healthy, active peers. (xi)

Beth Murphy is herself a journalist, but she put together a board of medical advisors to help her with this book. The chapters are unhurried and calming, with detail where it counts. When it comes to explaining things to the children, for instance, there is a separate section for each age: 2, 3-5, etc. The discussions of sexuality, fertility and pregnancy are careful and extensive. A new technique for preserving a woman's eggs prior to

chemotherapy shows up here, one I'd never heard of before. The chapters on alternative and complementary therapies are long, well-reasoned and informative.

As a bonus, throughout the book, are the words and experiences of young breast cancer survivors. They let us glimpse the subjective side of breast loss, of reconstruction, of fertility fears, of supportive - or unsupportive - partners. They tell us what worked, or didn't work, for them. They give us the words of encouragement we need to hear when facing set-backs or fresh bad news.

Most of the survivors interviewed for the book were met through the Young Survival Coalition, which can be connected to at [www.youngsurvival.org](http://www.youngsurvival.org). I've checked it out and it's well worth exploring. Another related website for women who's medical conditions have led them to hysterectomy is [www.hystersisters.com](http://www.hystersisters.com). Both of these websites are strong on support and personal contact.

## News

### Whatever happened to that ovarian cancer test?

**Round One.** It was called "OvaCheck," and it was based on the new science of proteomics, the study of proteins in living bodies. It broke on the scene in early 2004, and was reported here, among other places. The buzz at the time was that a simple blood sample could be run through this new protein testing system and it would reveal, 100% of the time, if ovarian cancer was present in the body, *even before* the cancer was detectable by other means. In a stroke, the problem of too-late discovery of ovarian cancer would be solved. Or so it seemed.

But there's many a slip twixt the cup and the lip. Several problems cropped up to turn OvaCheck into OvaCheckmate.

- Other labs could not duplicate the findings of the National Cancer Institute and FDA study that established the scientific concept behind the test. The test hinges on the detection of a pattern of proteins, using mass spectrometry and covering thousands of data points. Apparently, the complexity is such that subtle changes in testing procedures can cause one lab's outcomes to differ from another lab's outcomes.
- Outrageously (in my opinion), the private companies that developed the actual test, while they were using the scientific concept behind the NCI/FDA test, were not using the same measuring procedures or sample processing that the NCI/FDA used. And they were trying to bring the test to market without FDA approval, by working a loophole in the law.
- Then there was the issue of false positives.

Even if the research had been duplicated and the test developed more correctly, the false positives issue was a final hurdle that the test could not

have cleared. For use as a screening test on the population at large, the test must produce very few "false positives," that is, it mustn't tell you you have cancer when you don't. But the NCI test produced 5% false positives when tested on healthy women.

There's a formula, it turns out, for deciding how many false positives is too many. The frequency of the particular cancer in the population is balanced against the number of persons eligible to be screened. Only 1.8% of all women will develop ovarian cancer in their lifetime. But all women, in theory, were eligible to be screened. This meant that using the OvaCheck test, 5% of the *millions* of women eligible for the screening could test falsely positive and wind up having their ovaries out needlessly. At the very least they might set themselves up for ongoing transvaginal ultrasounds, laparoscopies and other tests, with risk of surgical complications and other follow-up issues. In effect, you'd be putting 5% of a large population through the wringer to catch the 1.8%. And think of the expense! Insurance companies would go into shock.

There are solutions to this last problem, other than improving the test. You can restrict the number of women eligible for the screening. You could, for instance, confine it to only women who are at high risk of ovarian cancer or its recurrence, e.g. women with a strong family history or women who have experienced a bout of ovarian cancer already. You can also make the "wringer" less costly and arduous by coming up with less invasive ways to determine whether the "detected" cancer is highly likely to be there. Secondary tests for other "biomarkers" or "proteomic patterns" in the patient's blood are a possibility. Both of these solutions are in progress.

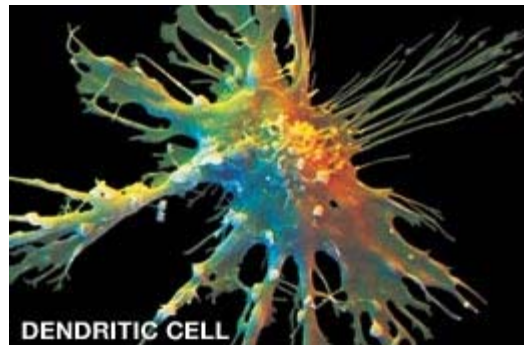
**Round Two.** Very recently, an ovarian cancer blood test came back on our radar screens, following a publication in the May issue of the Proceedings of the National Academy of Sciences. It's not OvaCheck, which is still tied up in controversy, but rather a simpler methodology that looks for elevated levels of four proteins. (The OvaCheck style of test looks for a pattern of proteins). Once again, it is only 95% accurate, so it would not be administered to women at large, but only to the high-risk.

Further up the pipeline, Johns Hopkins researchers report what may be an entirely new "proteomics profile" of ovarian cancer, and researchers at the H. Lee Moffitt Cancer Center in Tampa, Florida, report a possibly new "biomarker" for ovarian, comparable to the CA-125 that is now commonly used to follow women at risk for recurrence. This marker is called LPA, and it is already considered a better indicator of recurrence than CA-125.

With the population of women eligible for screening restricted, it is conceivable that in the not too distant future, a *battery* of blood tests, centered on an assortment of biological indicators, will emerge as the new standard of detection for ovarian cancer. Keep your fingers crossed. But don't hold your breath.

**Whatever happened to that prostate cancer vaccine?**

We learned in 2002, in the Duke Med News, that a prostate cancer vaccine made from the patient's own dendritic cells (a type of immune cell) was testing out as safe and effective in galvanizing the immune system to fight prostate cancer.



Now, in 2005, a phase II trial has been completed and the senior investigator on the study, Dr. Johannes Vieweg, Associate Professor of Urology and Immunology at Duke, reports that the promising results continue and there is a growing expectation that the new approach may fight other cancers besides prostate. This is because the immune cells are being trained to target telomerase, the protein that "immortalizes" cancer cells by renewing the telomeres ("chromosome tips") after every cell division. (Readers of our most recent newsletter on Cancer and Aging will recognize this concept.)

### **New hope for kidney cancer.**

Renal cell kidney cancer is infamous for its resistance to chemotherapy, which drastically limits the treatments available for it. But this may be about to change. Steve Dunn has it on his website at [http://cancerguide.org/rcc\\_bay43-9006.html](http://cancerguide.org/rcc_bay43-9006.html) that a new trial drug, BAY 43-9006, is generating a lot of excitement. A biological drug, rather than a chemo, BAY 43-9006 targets both a central oncogene for kidney cancer and two angiogenesis enabling receptors. This one-two-three punch is shrinking some tumors dramatically. Side effects are usually minimal. It is taken in pill form, which is good news in terms of ease of use, but possibly bad news in terms of insurance coverage. I refer you to Steve Dunn for further details and additional links.

### **Women can significantly drive back breast cancer through lifestyle changes.**

Two bits of good news are out regarding the prevention of breast cancer recurrence and prolongation of life for the breast cancer patient. Each should give a tremendous boost to women who want to feel that what they do at home can make a difference.

- The first finding is that *some* women substantially cut their risk of recurrence by going on a low-fat diet, even though they may never have dieted this way before their diagnosis. These are the women

whose cancers are *not estrogen-positive*. Non "positive" women are only about 25% of the breast cancer population, but for them, the news is dramatic. In the study, their recurrence rates dropped by a whopping 42%. And the diet itself requires only that one bring one's fat consumption down to about 33 grams/day which is not onerous.

- The hormone positive women have reason to rejoice as well, it turns out. The latest studies on the effects of moderate exercise on breast cancer survival show a distinct advantage - mainly to estrogen positive women - in survival time for those engaging in regular exercise. The life-extending effect held for the metastatic study subjects as well as for those fearing recurrence. To quote from the news report, "Of the 959 women who got the least exercise -- less than three hours a week -- 110 died of breast cancer. In comparison, of the 335 women who got three to five hours of exercise a week, only 20 died of the disease." In other words, the exercisers were only half as likely to die during the duration of the study compared to the sedentary women. (Earlier less rigorous studies have indicated that exercise confers survival advantages to virtually all cancer patients). Exercise may be as moderate as simply walking. The degree of protection increases with amount of exercise up to 3-5 hrs/week.

### Other Recent Additions to Our Collection

Thanks to the generosity of Chuck and Judith Jenkins, we now have 9 more meditation and stress reduction audiotapes in our collection. These include an 8 cassette series of meditations and healing images by Dr. Bernie S. Siegel; one rather hypnotic repetitive cassette entitled *Chemotherapy and Healing*; and one more of the ever-popular Jon Seskevich tapes entitled *Stress Management and Relaxation*.

Thanks to an anonymous donor, we now once again have a copy of *When God and Cancer Meet*, by Lynn Eib.

We recently purchased *Speak the Language of Healing: Living with Breast Cancer without Going to War*, by Carol Orsborn et al; *Lung Cancer: Making Sense of Diagnosis, Treatment and Options* by Lorraine Johnston; *What You Really Need to Know about Moles and Melanoma* by R. Jill et al; and *The Faith Factor: Proof of the Healing Power of Prayer* by Dale A. Mathews et al.

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