



SERVICES OFFERED

**GUIDE TO
COMPREHENSIVE
CANCER CARE**

**PATIENT / FAMILY
RESOURCE CENTER**

SELF CARE GUIDES

TESTS & PROCEDURES

**COMPLEMENTARY /
ALTERNATIVE CARE**

HOME

In the Know

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

June 2003

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 Clinic is 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

Resource Center Coordinator: Harriet Whitehead, PhD

Cancer Patient Education Program Director: Kerry Harwood, RN, MSN

Contents:

Reviews of books in our collection

- [Mom's Marijuana](#)
- [Pebbling the Walk](#)
- [Share the Care](#)

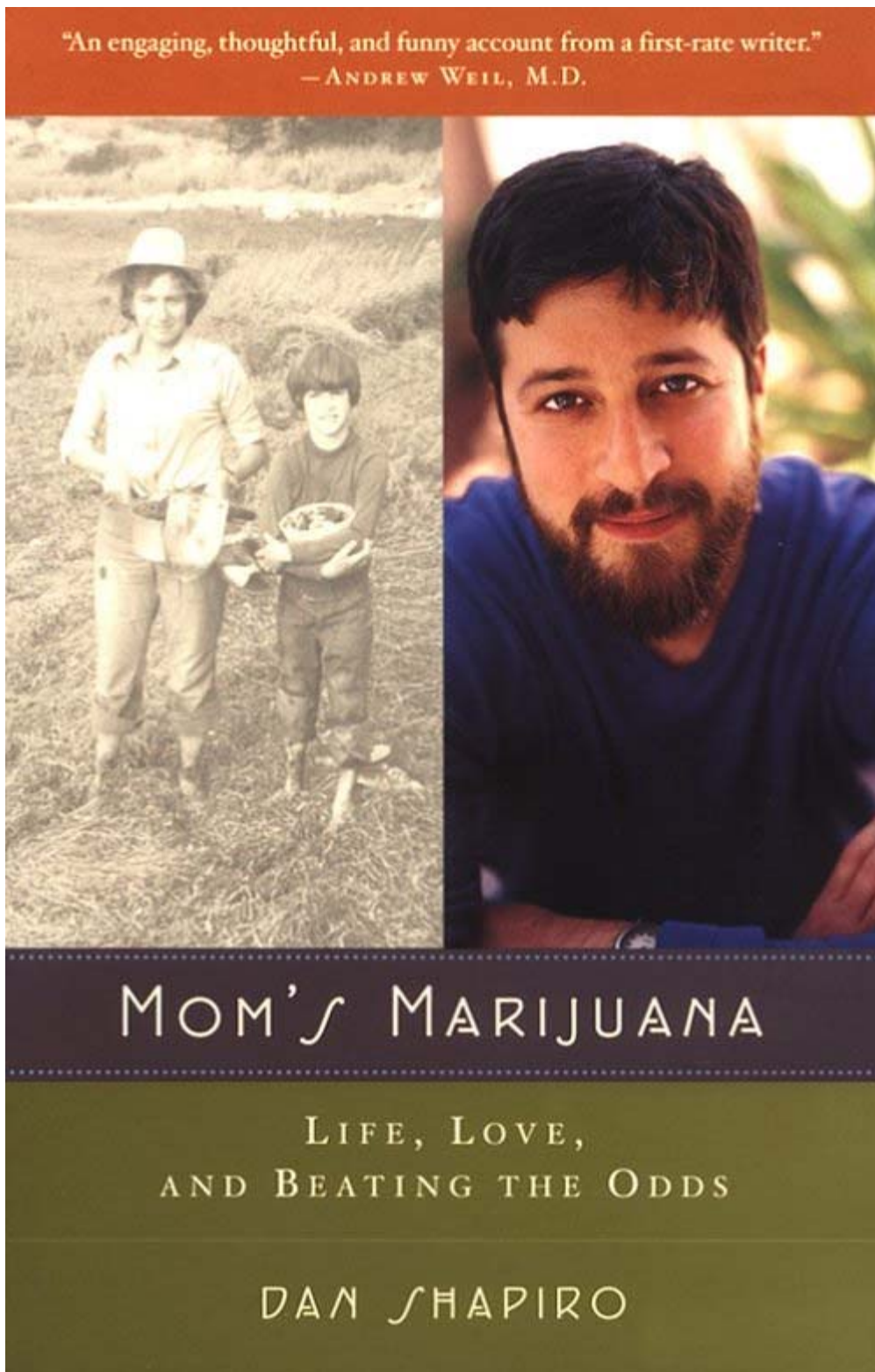
Website review: [Chemocare.com](#)

Duke services highlighted: Support groups from the Duke Cancer Patient Support Program

Books in our collection:

The Patient/Family Resource Center regularly adds new materials to our collection. This month, we highlight books about family members and friends in their roles as caregivers. Cancer can have a tremendous impact on those affected and studies suggest the emotional challenges may be similar between patients and close family members. Often family and friends are called on to do things they've never done before, and somehow manage to come through. You'll see this from various perspectives in these reviews.

NEW!



The Patient/Family Resource Library recently purchased this book because our collection was deficient in works on Hodgkin's Disease, the form of lymphoma that so often strikes young people. Anything readable on the subject was welcome. How gratifying to find that Dan Shapiro's cancer journey story far surpasses mere readability. Even if you aren't having a brush

with Hodgkin's, you might want to read it just to feel a little fonder of the human race.

The charming tale of his mom's backyard garden that opens the book puts to rest any notion that the author and his mom are erstwhile hippies. Drug use wasn't part of either's agenda until another young cancer survivor advised Dan, "Chemo is grim, man. Get weed." Initially shocked, mom did what she had to when a sick son's comfort was involved - she tucked those seeds from the first purchase behind her row of backyard sunflowers and let them grow. The eleven giant plants that resulted saw Dan through two relapses and a bone marrow transplant. Dan was diagnosed in 1987, but mom kept that last bag of home-grown until 1999 - just in case.

One gets further glimpses of Dan's unflappable mom, tenderhearted dad, competitive kid brother, and astonishingly cool new wife - along with a wide cast of lesser characters - as the book progresses. All are lovingly but unstintingly portrayed. In one wrenching scene Dan is peppering his new radiologist with his list of well-researched questions when both realize that Dan's dad is sobbing in the corner. Scarcely missing a beat, patient and doctor resume their tough-minded question session. Later the boyhood memory of being carried half asleep into the house from the car, pressed into dad's comforting chest, comes back to Dan as he lies forlorn in his hospital room. Shapiro has a great gift of memory and much of the appeal of his writing lies in his ability to weave together his sensually vivid past experiences with the present ones, making an earlier experience color a later with its humorous, comforting, or gritty aura. His hated high school wrestling coach crouched over him once after a brutalizing bout that left him gasping on the mat and growled, "You're OK. Get up." The remembered growl returns when

Ten years later I found my knees pressing on bathroom tile, wrestling's starting position. I was two months into salvage chemotherapy, wearing down. I'd had shingles and mouth sores and had lost twenty-five pounds. While looking at the porcelain ring after releasing everything in my stomach, a thought occurred to me. *This is terrible.* It led to *Why me?* And more. I was just getting momentum, the litany swirling together into a serious pity fest, when I heard that annoying gravelly Midwestern voice: "You're OK. Get up."

My favorite of these stories concerns his mom, once again. Not just an avid gardener but a sublimely confident birdwatcher, mom once stared out the window of their suburban Connecticut home and blithely announced to her birdwatcher husband

"Oh, honey, look, a Crested Auklet!" My father flung away his crossword puzzle and raced to the window, knocking over a chair in the process. "Where, where?!" he pleaded, looking eagerly into the backyard. She stretched a finger toward a

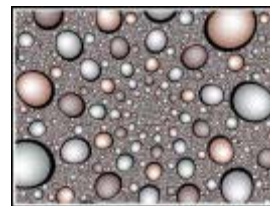
birdfeeder, but then it dropped. "Oh darn. He's gone."
 "Did you say Crested Auklet?" he asked incredulous.
 "Well, it could've been a Whiskered Auklet, but they're rare."
 He fingered through the bird book. "Hmmm." Skeptical. "It says here Crested Auklets are only seen on the Aleutian or Shumagin Islands off Alaska." My mother responded, "Yeah, honey, that's why I'm so surprised. How exciting. I only feel bad because you didn't get to see it." She then carefully wrote the date of the sighting next to the picture of the bird in her book. *Crested Auklet, dining room window, August 14, 1978.*

A few days after Dan's bone marrow transplant, his parents came to his room.

Mom greeted me. "You look great. Your [blood] counts are improving, aren't they?" Behind her my father surveyed the chart. Squinted at it. "Say's here his counts are zero," my father reported. Mom studied me. "He looks good to me. He's got more color, he's more alert, and his skin tone isn't so blotchy. Yup. That chart's wrong. His counts are improving, I can tell... You'll be out of here before you know it," Mom declared. I was skeptical, but the next day my counts were significantly better. And even better the next, as she continued to predict. And to this day, I'm sure that somewhere, in a familiar backyard in northern Connecticut, there's an Alaskan Crested Auklet, and, by now, a whole extended family, enjoying their new home.

Not every tale in the book is as lighthearted as these excerpts may imply. Shapiro is vivid, even in torment, and makes no attempt to mask the severity of his struggle, especially in the nadir that followed his second relapse. But every tale, however disturbing, wraps the reader, eventually, in a heartfelt life embrace. This is a man you wish you were friends with. This is a man whose death, had it happened, would have left us all the poorer. As it is, he is alive and thriving at age 34, now a practicing psychologist and the father of two daughters. Never bashful about book titles, he plans to call his next book *House of Estrogen*.

Pebbling the Walk: Surviving Cancer Caregiving by Steve Reed.



We who are caregivers do so for one reason only. We want to contribute to the battle in some way - Steve Reed.

Steve Reed, a professional writer, has done more than his share of

contributing to the battle. Coming from a cancer afflicted family, he has given end-of-life care to a younger brother and younger sister and to his step-father, while earlier pitching in with help for an aunt and for his mother. As this book was being written he was helping to pull his wife, Marthy, through a treatment regime for breast cancer. A lot of his life and spirit have gone into cancer caregiving.

He has some good advice for all of us. I found his chapter on feeding the patient eminently sensible and his quick guides to handling tricky emotional issues useful and reassuring. But the heart of the book lies in his special insights into spending meaningful time with the patient. In most advice books, we're led to believe that heartfelt one-on-ones and tearful family reconciliations are the essential experiences to introduce into the life of a dying (or potentially dying) patient. Reed has no particular argument with such needs. But he brings to the foreground a different and equally important level of sociability: just mooching around. In the book's title chapter, "Looking for Four-Leaf Clovers or Pebbling the Walk," he explains,

Oddly enough, when time is short is the best time to waste time, to idle afternoons away doing nothing productive at all - nothing but spending time together... Of all the things I did with my brother during the thirty-eight years of his life, the days we idled away doing nothing except talking and looking for four-leaf clovers are among the most memorable.

With Reed's wife, the activity was finding beach pebbles suitable for their walkway.

The discipline of strolling the beaches...seeking pretty pebbles for our path became a metaphor for all that was meaningful in our lives.

Our ancestral foraging pattern is the activity invoked in both these examples but the deeply comforting co-presence associated with joint foraging can be brought about in many other ways, as anyone who has collectively quilted or knitted or painted a room can testify. Productivity probably has nothing to do with it. Shared non-urgent activity seems to be the key.

I have some quibbles with Reed's sometimes sappy philosophizing (e.g. life is a "field" that contains "clovers" but also "cow pies"); and at points I was bothered by what seems to be a total ignorance of cancer - is it just his wording or did he really think his dying step-father kept developing new primary cancers? These considerations aside, *Pebbling the Walk* is a book I want on my shelf and one that I urge other cancer caregivers to read.

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill by Cappy Capossela and Sheila Warnock

This is far and away the most hopeful book on heavy-duty outpatient caregiving. When faced with an eldercare or illness care crisis, did you ever think you would hear the words, "You don't have to..." without feeling guilt? Well, read on. "You don't have to do things you don't want to do, you don't have to do things you are afraid to do, you don't have to do things you feel you're not good at," say our authors. "The power is in the group. Among all of you is the solution to any problem."

Between these covers is a complete how-to manual on setting up a care-sharing group that will continue to function for several years if necessary and out of which everyone emerges enriched. Too good to be true? I certainly hope not. The authors first introduce you to the case that launched their method, that of a terminally ill cancer patient friend. Hearing how well their approach worked is an eye-opener in itself. Then they get right down to the nuts and bolts of how to organize a care-giving group for one's own situation. It takes planning. It takes nerve. It takes some paperwork. But it works!

Website Reviews

CARES: Cancer Alliance for Research, Education and Survivorship



Scott Hamilton (on right), the Olympic figure-skating champion, is a survivor of testicular cancer. He joined with the Cleveland Clinic Cancer Center to

launch an initiative entitled "Scott Hamilton CARES," the acronym standing for "Cancer Alliance for Research, Education and Survivorship." It is this initiative, under the sponsorship of OrthoBiotech*, that brings us the useful website www.chemocare.com

Go to Chemocare for a knowledgeable report on your chemotherapy drug - who gets it, what it's made of, how it fights cancer, what its side effects are. Equally useful are the discussions on "Managing Side Effects," "Eating Well During Chemotherapy," and "Before and After Chemotherapy." In addition, the site links you to survivor stories, news, message boards and advice on complementary therapies."

We have spent some time on this site and find it medically up-to-date, thorough and well written. Click on Chemotherapy Drugs and a list comes up that can be seen by scrolling down. If you aren't sure how your drug's name is spelled, check the list first and click on the drug when you find it. (There is a list both for the brand names and for the generic spellings.) Or if you have the spelling you can type the name directly into the search function, then click again on the name that the search brought up. You should wind up with a long page that takes you through pronunciation of the name, other names for this drug, what the drug is used to treat, how its administered, its side effects and the way it fights cancer.

*OrthoBiotech is the drug company that manufactures Procrit, a support drug that fights the low red blood counts that some forms of chemotherapy may cause.

Duke services highlighted: Support groups from the Duke Cancer Patient Support Program

The Duke Cancer Patient Support Program is here to help cancer patients and their families in a variety of ways. If you need directions, an understanding listener, some company in the evenings when you're hospitalized, or just coffee and some cookies while you wait in the clinics - all are provided free of charge by the Cancer Patient Support Program. The program also offers support groups and individual and family counseling, also free. The main office is located in the same lobby of the Morris Building as the Patient/Family Resource Center, right across the corridor in room 15121.

The following support groups, all held at Duke, will be running through the winter: Prostate Cancer, Breast Cancer, Breast Cancer for Women 40 Yrs and Younger; Living with Breast Cancer as a Chronic Illness; Gynecological Cancer, Head & Neck Cancer, Leukemia & Lymphoma, Lung Cancer, Multiple Myeloma, Gastrointestinal & Pancreatic Cancer, Living with Cancer; Look Good...Feel Better (hair and cosmetology workshops); and Meet with Family Members of Other Cancer Patients. For exact times and places, call 919-684-4497.

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Designated by the National Cancer Institute