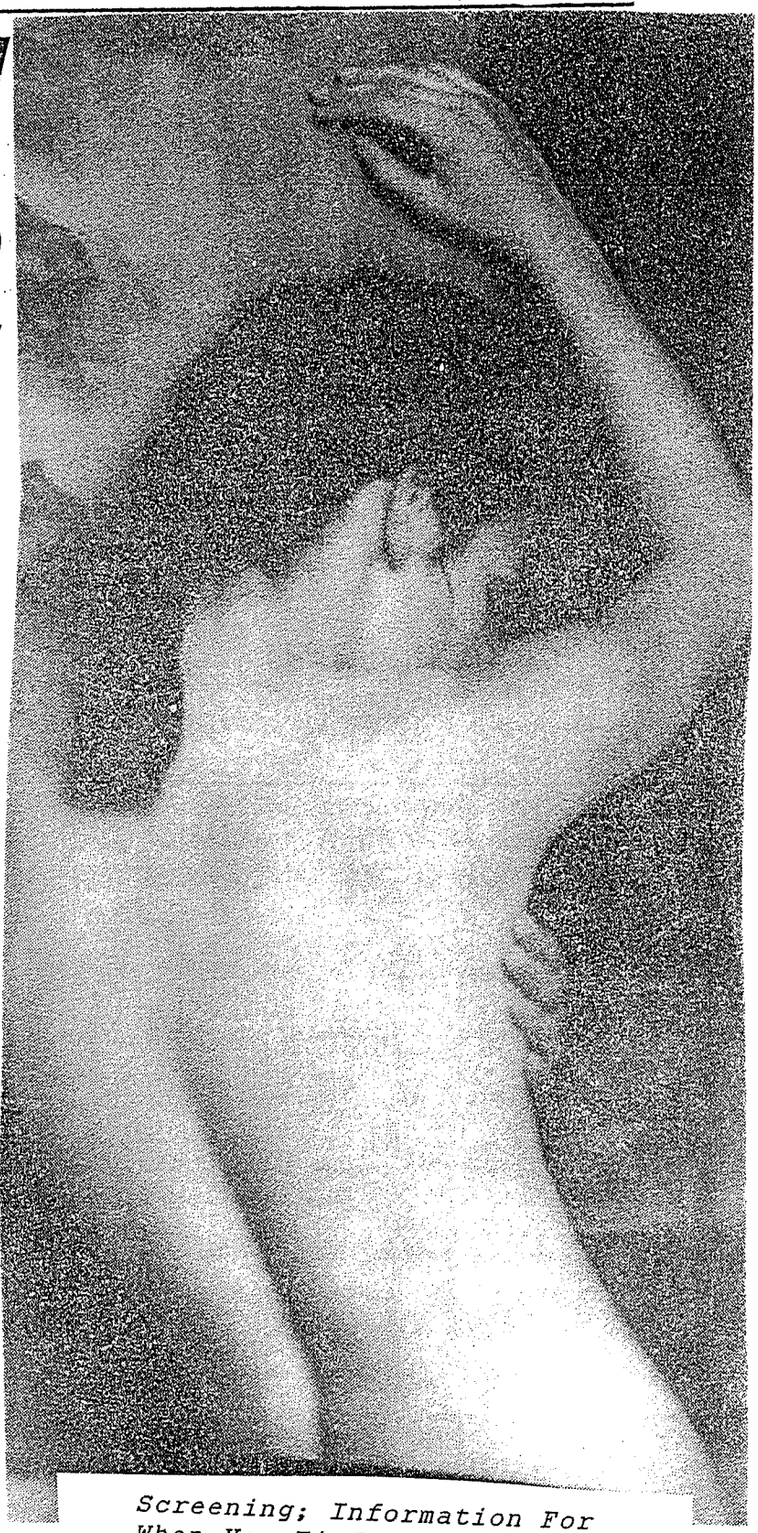
AWARE

NEWSLETTER PUBLISHED BY ANTIGONISH WOMEN"S ASSOCIATION
RESOURCE CENTER 863-6221 **OCTOBER** 95

BREAST CANCER

Awareness month



October is Breast Cancer Awareness month so we are taking this opportunity to cover this topic in the Fall edition. There are not many of us whose lives have not been touched by this life threatening disease. The statistics are very high - one in nine women. We have heard it described as epidemic proportions and we have to take it seriously. In this issue we have tried to compile information that will be useful to women especially with the goal of prevention in mind. We have two workshops on Breast Self-examination planned for November and December. Look for details on back page.

Women's groups, community organizations and professional associations in the Atlantic provinces are taking part in a project to distribute accurate, up-to-date breast health/breast cancer information throughout the region. With help from hundreds of organizations, ranging from the Acadia Women's Centre in Nova Scotia to the Lions Clubs of Prince Edward Island, the Atlantic Breast Cancer Information Project (ABCIP) is sending out over 45,000 order cards across the four Atlantic provinces.

This special initiative for *Breast Health Month* provides an easy way to order information on the following topics - *General Breast Health; Mammography/ Breast Screening; Information For When You Find a Lump or Changes in Your Breast; Breast Cancer Information and a List of Books, Pamphlets and Videos; Breast Cancer Services, Treatment Centres and Support Groups in the Atlantic Region; Latest Breast Cancer Research; Unconventional Therapies; and Internet Information Resources.* Women simply check off the topics they are interested in and mail the cards back to their provincial Canadian Cancer Society (CCS) offices whose staff will send out the information requested.

For more information about any of the above-mentioned projects, contact Tamara Casebolt or Anne McCallum, Atlantic Breast Cancer Information Project, 1 Rochford St., Suite # 1, Charlottetown, PEI C1A 3T1 Phone: (902) 892-9531.

INTERNET RESOURCES

CANADIAN PAGES

Breast Cancer Action
http://infoweb.magi.com/(tilde)bcanet/

Burlington Breast Cancer Support Services
http://wchat.on.ca/web/bbcss/

MAJOR PAGES

Oncolink
http://cancer.med.upenn.edu

Breast Cancer Information Clearing House
http://nysernet.org/bcic/

OTHERS

Information on breast self examination
http://www.net-advisor.com/mammog/

Community Breast Health Project
http://www-med.stanford.edu/CBHP/

Arlington Cancer Center
http://www.pic.net:80/uniloc/acctx/

American Cancer Society index page
http://nysernet.org/bcic/acs2/index.html

U.S. National Cancer Institute
http://www.nci.nih.gov/

Cancernet
http://www.arc.com/cancernet/cancernet.html

Avon's Breast Cancer Awareness Crusade
http://www.pmedia.com/Avon/avon.html

MAILING LISTS

breast-cancer
e-mail listserv@morgan.ucs.mun.ca with SUBSCRIBE BREAST-CANCER in the body of the message

cancer-l
e-mail listserve@wuvmd.wustl.edu with SUBSCRIBE CANCER-L in the body of the message

CANCER FAQ

Huge list of on-line resources
http://www.cis.ohio-state.edu/hypertext/faq/usenet/cancer-faq/

A SURVIVOR'S STORY

BY MARY E. CARTER

THERE'S PROBABLY no great time to discover that you have a life-threatening disease, but mine came at the worst.

It was early March, 1991, and my partner and I had just sold our house, having decided to give up on housing as a retirement nest-egg strategy. The deal had a short, six-week close. Almost immediately, it seemed, I found The Lump, and had to contend with that as well as finding a new home and moving.

Not being a regular practitioner of breast self-examination, I guess I shouldn't have been totally thrown when I found The Lump while showering. But golly, I *had* had a medical check-up sometime in the past two years. The doctor was very apologetic, which hardly seemed adequate, but I had bigger worries than his competence.

He referred me to the big downtown Toronto hospital he was affiliated with, and my encounter with the world of cancer was off and running.

On March 11, I went to the hospital's breast-screening clinic, full of brightly clad and cheerful volunteers. I had a mammogram and then, while a volunteer tightly held my hand, a fatherly doctor did a needle aspiration. The verdict: it was serious, and the volunteer held my hand even more tightly as I fought tears.

For someone who had never been near a hospital except to visit friends, it was decidedly a low point.

I don't know how many women this happens to, but I found myself reacting by becoming the World's Best Little Cancer Patient. I informed my friends almost apologetically, hating to ruin their day.

My massage therapist, a font of good info at the best of times, was just as reliable when told the news. As well as lots of cheering up, she gave me the names of doctors in the Toronto area who enlisted alternative treatments, from macrobiotic diet to "horse medicines," as well as the number of a California foundation where they advise a range of treatments available for my cancer type.

I couldn't remember, then or now, exactly what type my breast cancer was, except that it was advanced — the doctor who did the needle biopsy said it had been growing for about seven years — and might have spread to my lymph nodes. Call it denial, but I didn't need to know any more than that it was something to be taken seriously indeed.

The surgeon I saw at the hospital was young and exuded confidence. He checked me out and set up a surgical biopsy on March 20. Things were moving right along — not because that is the norm in our overworked medical system, but because I was a candidate to participate in a large study. Women in that study, run by the National Surgical Adjuvant Breast Project based at the University of Pittsburgh, had to be operated on within two months of the fine needle aspiration. In my case, that meant by early May.

The study wanted to look at whether chemotherapy given before surgery could prolong survival, disease-free and otherwise. The drugs would be an aggressive combination, Adriamycin and Cyclophosphamide, given in a short, intensive course — four cycles, one every 21 days. In addition, women over 50 would get the antiestrogen drug Tamoxifen daily for five years.

I had the surgical biopsy, a same-day procedure with a local anesthetic. After the sample was removed and rushed off to the pathologist, the surgeon and an assistant discussed new cars while parked across my chest awaiting the results.

The news was bad, but by then I was getting used to bad news. The surgeon advised me that because of the tumour's size, a lumpectomy was not an option. We were talking mastectomy.

I looked at the consent form for participating in the study. Some alarming phrases popped out at me: the chemotherapy drugs made you more susceptible to bruising, bleeding or infection, diarrhea, vomiting, nausea, mouth ulcers, complete hair loss (usually not permanent), possible weakening of the heart muscle. Thanks heavens I wasn't a candidate for Tamoxifen, whose possible side effects sounded like the menopause from Hell.

At that point, I decided to go for a second opinion. Someone mentioned an experienced surgeon up at a large suburban hospital and clutching my X-rays, I paid him a visit. He suggested a six-month pre-surgery course of chemo and radiation, after which the tumour — now about six centimetres long — might shrink to lumpectomy size.

I was getting into a bit of a panic — radiation struck me as even scarier than chemo — but a couple of things happened around then that helped.

Someone I worked with mentioned that their Aunt Betty had had a mastectomy 20 years earlier. Was she still around? I asked. Oh yes, he said ... and she seemed okay, except that one arm had swollen up a lot.

Hearing that, I relaxed and started to think I might make it through this.

The second thing was discovering a book called *Surviving Breast Cancer,* by Carole Spearin McCauley (Seal Books). It was full of useful information and survivors' stories, but its main message was that you did a lot better if you took charge of your treatment.

I was open to alternatives, such as changing my diet, cutting back on alcohol, exercising more and doing visualization. But part of me felt positive about standard medical strategies such as surgery and even chemo. Let's throw everything useful at it, I thought.

I decided to go with the younger surgeon. To my relief — given the size of my tumour — I drew the surgery-first wing of the study. We moved into our new home on April 26 and a few days later, I was in the downtown hospital, set for surgery on May 1.

In 1991, the news stories about breast implants were pretty scary and I decided against breast reconstruction. I was going to be an Amazon: archery, anyone?

Once in hospital, I followed my naturopath's advice, taking gelsenium ("for fear of procedure") and lots of arnica. I was miffed not to have a private room, having paid for one for years, but that was the least of my worries.

The day after surgery, I was in pretty good shape . . . eating well, normal temperature, just a drip bag attached to one side. But I quickly found out the joke was true: hospitals are expensive hotels with bad food. After three days, I persuaded the doctors that someone else could make better use of my bed, and they let me go, drip bag and all.

I had taken a four-month leave of absence from work, not knowing if the chemo was going to be as bad as all the stories I'd been hearing.

It *was* hard to take, but not because of the side effects. My first visit to the chemo ward seemed endless. My "appointment" was at 9, and my intravenous medication hadn't shown up by noon. I had had blood samples taken, but that was all. Upset, I yelled at some nurses that I was leaving. Underneath, I was probably just scared. They made sympathetic noises and finally got me hooked up.

I ended up feeling angry every time I went to in for chemo. Not because of the side effects — which were almost nil, until toward the end, when my hair and I did indeed part company — but because of the seeming indifference to patient's schedules. As well as the medication delays, my oncologist seemed to operate in a whole different time zone.

But I survived, and after three years of quarterly follow-up visits, some involving bone scans, X-rays, blood tests and such, I "graduated" to semi-annual visits. My oncologist moved to a new, brighter cancer centre and my follow-up visits became more fun. Once, I showed up with a temporary tattoo on my chest and said I was thinking of having a permanent one. The resident checking me out said without blinking that that might hide one of the trouble signs, discolouration.

This May I passed my fourth annual. After five years, you "graduate" again — to annual checkups. I can hardly wait.

Since the day the raven landed on my shoulder, I've been given some great gifts, including my partner's unfailing support. A miraculous connection got me into a 12-step sobriety program. That seemed to open my spiritual side: I'm meditating now and studying Buddhism. I'd like to become vegetarian, if not fully macrobiotic. I walk to work whenever possible, in addition to long daily walks with my dogs.

Having a long-term dream is important to surviving cancer, I think, and we've bought a farm property up north we are fixing up for retirement. But living in the moment has become easier.

With breast cancer, they never wave a wand and say you're better now. People die as long as 20 years later. But I'm optimistic.

Thanks, Aunt Betty, wherever you are.

Mary E. Carter is a pseudonym for a Toronto editor and writer.

NEWS FROM THE CENTRE

by Katherine Reed

Watching the Women's Centre grow is an awe-inspiring experience -- kinda like when my teenaged sons suddenly turned into young men almost overnight. The past few months have seen 5 staffing changes due to projects and placements beginning and ending, we have handled a total of 1568 calls and visits since June 1st. ... a rather busy summer. A telephone-based service for survivors of sexual assault, sexual abuse and non-offending parents of children who have been sexually abused began with a contingent of 9 well-trained volunteers. Some work has been done toward getting the Centre on-line, so staff and women using the Centre can surf the 'Net for the latest on a wide range of interest areas.

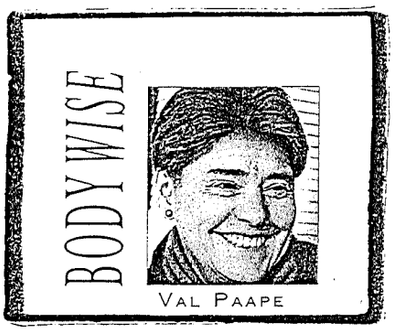
The Sexual Assault Project has come to an end, but the work of implementing the directions suggested by the Project is just beginning. Three community-based committees have begun this process. This activity could make a huge difference in the post-trauma experiences of sexual assault and sexual abuse survivors.

The Annual "Take Back the Night Walk" was very well-attended by a diverse group of women. Thanks go to everyone who helped plan and coordinate this event. It is so important to do this awareness-raising and to experience the power of women coming together to demonstrate our concerns to the community.

Self-help groups continue to use the Centre for meetings, phone messages and resources. Community committees also use the space for meetings, and this is a fantastic way to let the people who come into contact with women on a daily basis know how the AWRC can serve women and the community.

One of the issues the Centre will be concentrating on in the coming months is the dramatic change in the way the federal government transfers money to the provinces for health, education and social services. There are massive cuts coming and reform processes that will have a huge impact on all of us whether we are ill or well, rich or poor. Please check in to the Centre for news on your area of interest, and get involved in your church group, union, or the AWA.

As usual, you are encouraged to drop by anytime and check out what is buzzing at the Centre. I promise, it will always be interesting and exciting. Come out to the Friday Brown Bag Lunch get-together on Friday at noon. Happy Hallowe'en!



Getting to the Heart of our Fear of Cancer

My father suffered from diabetes and cerebrovascular disease. My mother has had two TIAs (temporary ischaemic attacks) or minor strokes. My parents are average North Americans. Most North Americans die of heart and/or cerebrovascular disease. Despite my family history, which fails to include breast cancer, my fear is that I will die of that dreaded disease rather than keel over from a heart attack.

If you ask a random group of women to cite what they believe to be the number one cause of women's deaths, many would probably answer breast cancer. But according to "Women In Canada," a 1995 report by Statistics Canada, in 1992, death from breast cancer ranked fifth after heart diseases, cerebrovascular disease, respiratory disease and lung cancer. Breast cancer accounted for only 5% of all deaths compared to 37% for heart disease and stroke. If these figures were used to project the probable cause of death amoung a random group of women, only 1 in 20 would die of breast cancer while 4 in 10 would die of heart and cerebrovascular disease.

Breast cancer has been of tremendous concern to women and has had considerable media coverage in the popular and the alternative press. Due to the controversy concerning mammogram screening, the possibility of increased risk due to hormone replacement therapy and feminist analysis of health care, we know a lot about the health issues related to breast cancer. But have we over estimated its risk? Despite the fact that the average woman's risk is only 1 in 20, routinely 1 in 10 is bandied about as the relevant statistic.

While we have become more informed (and more fearful?) about breast cancer, we have been unaware of the high mortality from heart disease and stroke. Are we so caught up in the specific diseases and conditions of our sex that we have forgotten that the most deadly diseases are those we share with men? Our knowledge of heart disease often comes in particular contexts; e.g., the risk of heart attack due to a blood clot is greater for women who smoke and are on the pill, or heart attack is very rare in women under 50, presumably due to pre-menopausal estrogen protection. In health books targeted at women, the information about heart disease is often chopped up like this so that, essential and accurate as the information might be, it leads us to conclude that, on its own, heart disease is not a particular threat to women. And, our societal attitudes toward heart disease and cancer are worlds apart. Heart disease appears to be a respectable disease of old age, inevitable for anyone who hasn't yet succombed to anything else. Cancer, on the other hand, is a dreaded, painful, dehumanizing disease that may even be our fault. New Age "wisdom" would have us believe that repressed anger and unhappiness causes cancer.

The *real* reason why the risk of heart and cerebrovascular diseases is not seen accurately is because the critical mass of feminist indignation has yet to be aroused. Consider the following facts: women have twice the mortality rate of men after suffering heart attack; women are more likely then men to die after bypass surgery, angioplasty (flattening cholesterol against the artery walls) and blood-thinning therapy; prescribing calcium-channel antagonists (reduces stress on the heart muscle) to women may increase their mortality rate; and, male patients are more apt to be prescribed nitrates and blood thinners while women are prescribed Valium derivatives and drugs for the gastro-intestinal tract. In Canada, one study has reported that three times more men than women get intervention treatment following diagnosis of heart disease, even in the 65 to 74 age group where the incidence of heart disease is equal. Do we know why any of these are true? No. ("The Big Unknowns of Women's Sickness", The Globe and Mail, March 3, 1995)

The fact that women respond differently to blood thinners like Aspirin points out the flawed nature of medical research. The famous US Aspirin study may have shown significant preventative effects for heart disease but it was conducted only on male physicians. Even when both sexes and minority groups are included in reseach to satisfy funding requirements, the results are not necessarily statistically analyzed accordingly.

Heart disease and stroke are the hidden diseases of women. In 1995, Women's College Hospital in Toronto conducted a survey of women's knowledge about health issues. Only 16 percent correctly identified the risks associated with heart disease.

The medical profession has failed to research important areas concerning heart disease and women or to treat women effectively. This situation will not change until women are knowledgable and demand higher quality treatment. Breast health advocates did a good job of bringing us the issues and the information Perhaps we can use some of their methods as a model to provide the necessary information to women about heart disease and stroke. We need a balanced view of our health concerns which accurately reflects our risks without generating undue fear and anxiety.

Val Paape keeps abreast of all women's health issues affecting mind, body and spirit. She works at the Yoga Centre in Winnipeg.

SEVEN STEPS TO HEALTH

The Canadian Cancer Society offers these Seven Steps to help prevent cancer:

1. Choose to be a non-smoker and avoid second-hand smoke.

2. Choose a variety of low-fat, high-fibre foods. Maintain a healthy body weight and limit your alcohol intake.

3. Protect yourself and your family from the sun. Practice regular skin examinations and report any changes immediately.

4. Regularly scheduled Pap tests and mammograms, according to age, are vital. Practice monthly breast self examination.

5. See your doctor and dentist regularly for checkups.

6. Be aware of changes in your normal state of health. If you discover a lump or a mole that has changed, or a sore that won't heal, check with your doctor immediately.

7. At home and at work, follow health and safety instructions when using hazardous materials.