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Healthsharing

A CANADIAN WOMEN'S HEALTH QUARTERLY

BREAST CANCER IN THE '80s

Treatment

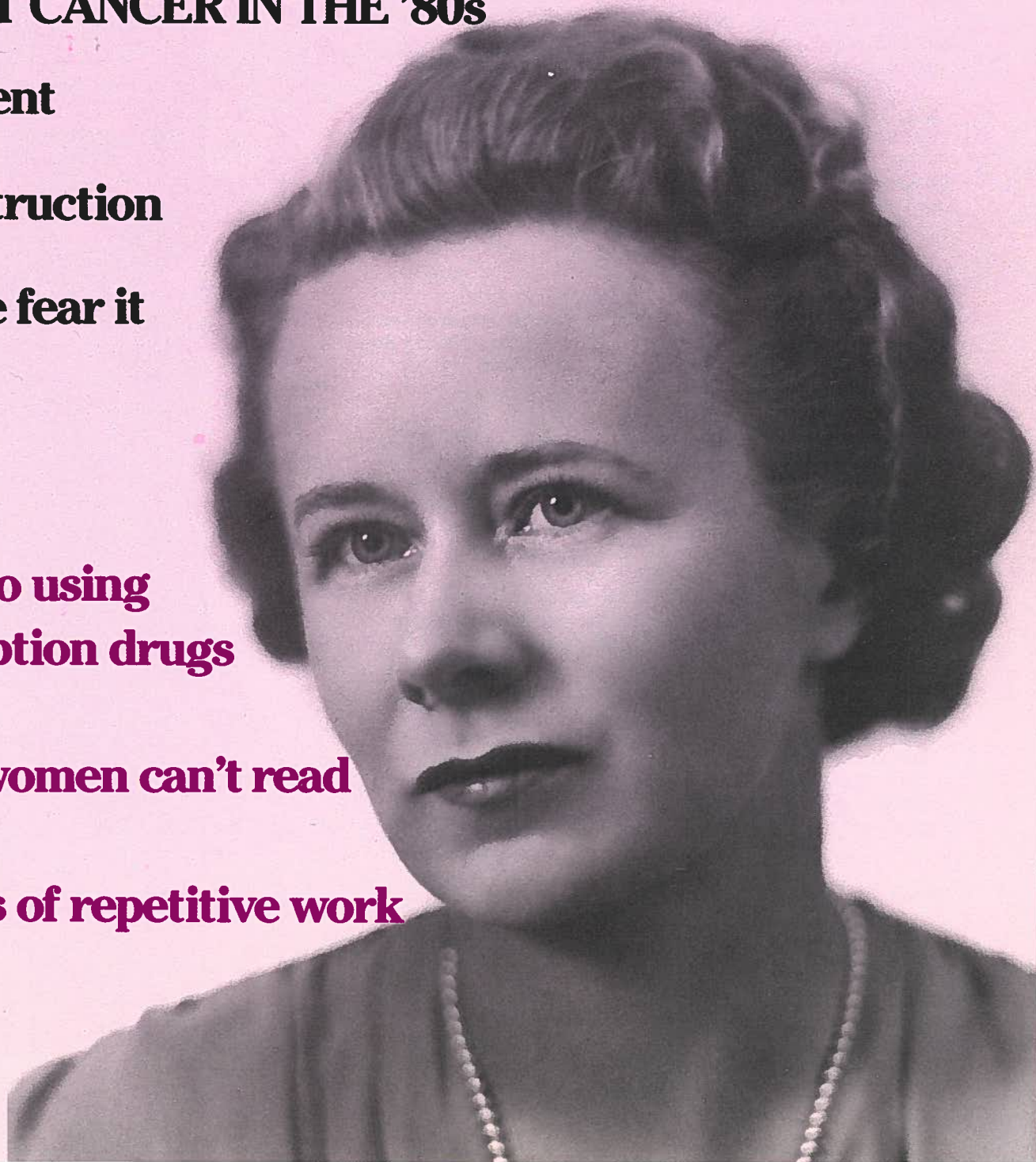
Reconstruction

Why we fear it

**Tricks to using
prescription drugs**

When women can't read

Hazards of repetitive work



INSIDE

Healthsharing

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Ida Wellwood

COLLECTIVE NOTES

Cancer: Cure or Care

Each of us in Women Healthsharing has had cancer touch our extended family or friendship circles. Each of us has seen the fear of cancer become a concrete reality.

Cancer... our discussion to write this *Collective Notes* was far reaching, spinning out and touching emotions, science, medicine, women. We are glad to see a trend toward cancer beginning to be normalized. Credit for reducing secrecy and shame goes to the many individuals with cancer who, like the women in this issue, have shared aspects of their experience with others.

The fear can be hardest to break through. And the fear is one reason why it is difficult for women facing cancer to be active 'consumers' of health care, a challenge and contradiction at the best of times. It's not as though there is a set amount of health around and if you just ask the right questions at the right time of the right health practitioner, you can be assured of having some. The buyer beware approach to using health services *can* significantly improve treatment, yet, it must be recognized how immensely difficult this can be.

The two articles about breast cancer in this issue each encourage women to be the final judges of their own medical options — women need skills and support to do this. Especially when confronted by the potential or known fact of cancer, we need to make use of feminist practice — the group process, communication and support skills feminists have developed. If you do find yourself facing cancer, don't be pressured into taking blame for the cancer onto yourself — no one knows enough yet to know what you could have done to prevent the cancer. Find someone to help you face the fear, in whatever manner is best for you.

We suggest that women with cancer or cancer risk find a buddy. Ask the

buddy to undertake research, to be your advocate by accompanying you to meetings with doctors or to labs for tests, to be a steady supporter whom you can call on at odd hours. Choose someone close enough to know you, but not so close as to lose sight of her own counsel. Here we're speaking about the early stages of cancer diagnosis or cancer development; with advanced cancer, groups of people are needed to support someone in the act of dying. Nowhere is this process described more beautifully than in June Callwood's moving *Twelve Weeks in Spring*, the story of Margaret Frazer's dying.

It's difficult to be an informed consumer of health care for cancer, particularly when even the specialists don't fully understand how and why cancer develops. There is by now agreement that some individuals have a biologically greater risk of developing cancer than others and this risk is in part controlled by exposure to cancer 'promoters' (chemicals, hormones, dietary elements and the like which trigger cancer).

Much attention has focused on early detection and overtreatment. Breast cancer used to be conceived of as a progressive disease (spreading from the breast to the lymph nodes under the arm to other parts of the body). This viewpoint was the reason for the extreme surgery of yesteryear — 'get it all before it spreads' — and the emphasis on early detection. Now it is thought that some breast cancers spread to other parts of the body *before* a lump can be detected; other breast cancers grow slowly and are unlikely to spread, perhaps even if left entirely untreated; most breast cancers are probably somewhere in the middle. This viewpoint is responsible for the trend toward less invasive and less mutilating surgeries, which are proving just as effective... and emo-

tionally, less is nearly always best.

With the advent of early detection techniques, such as X-rays of the breast called mammograms, it was thought that mortality related to breast cancer would decline. This has not been the case. It's true enough that post-treatment years of survival have gone up: there are more women living beyond the five year mark medicine claims as the cure point.

Because of these statistics some scientists argue that early detection and early treatment, for *some* cancers, is not affecting the time of death. Let's imagine a woman whose cancer began in 1975. In one case she found the lump by manual detection in 1982, had surgery and died of cancer elsewhere in her body in 1986. Her death was four years after detection and so she wasn't considered cured. Then imagine if the same woman had a mammo-gram in 1980, found the tiny lump and had surgery... just as in the first case, she died of cancer elsewhere in the body in 1986. This time her death came six years after detection and she shows up in the statistics as cured. The start of cancer and her death were the same, but medicine claims early detection and treatment to have cured her in one case. Somehow there is something wrong.

What are the implications? It appears too early to know. For most cancers, which grow at a medium speed, early detection and treatment are likely to be of great benefit. We're not suggesting that detection and treatment aren't important — far from it. Learn what you can when you're healthy. Learn how to do breast self-examination. Be sure your doctor does a full examination at your annual check up (including the lymph glands and not just the breasts). Learn about diets that might help prevent cancer. If you're one of the fortunate who can readily reduce the stress in your life, do so — it will help in more ways than reducing your chances of developing cancer!

Elizabeth Amer, Amyra Braha, Connie Clement, Susan Elliott, Deborah Feinstadt, Alice Grange, Connie Guberman, Diana Majury, Lisa McCaskell.

LETTERS

We encourage readers to write. Your debate is just as vital as the original articles and columns published in the magazine. Please take the time to share your opinions with other readers.

Healthsharing reserves the option to print letters edited for length, unless they are marked 'not for publication.'

Emerging strength

I have just finished my Masters degree (finally!) and am seriously considering putting in a proposal to do some menopause workshops/research. It seems that many women still have very little information about and many fears surrounding menopause. The whole area of mid-life is

especially interesting to me and I did my graduate work in this area. Women go through many changes, psychological as well as physical and it can be a time of emerging strength and personal power, although this is often not the expectation socially imposed. I am so glad your journal devoted an issue to menopause and helped encourage open dialogue by so doing. I think it is exciting!

Mary Madsen
Burnaby, B.C.

Love and sex after cancer

Thank you for running my notice under *Health Wanted* in the Winter, 1986 issue. So far there have been four responses, for which I am grateful. While this sounds like a very low response rate, I've learned that threatened sexuality is a very difficult thing for us to talk about (which only convinces me that there is a need for my book and more books exploring female sexuality and the broader area of intimacy).

Thank you for your help; and for *Healthsharing* — I've just received my first issue and found every article useful and well-researched.

Jacquelyn Johnson
Powassan, Ont.

Electro-shock findings rejected

I am writing to respond to an article in the Spring, 1986 issue by Deborah Feinstadt. Electro-shock Therapy (ECT) is the most controversial treatment for psychological disorders and the subject of impassioned debate. Even with the advent of new drugs and

therapy, 60,000 to 100,000 people per year receive ECT. ECT has been used continuously for more than 40 years, longer than any other physical treatment available for mental illness. It has achieved this longevity because, when administered properly, it can help as much or more than any other treatment. ECT is particularly effective for people who do not respond to anti-depressants. In actual practice today, it is used mainly with these patients.

While there are dangers associated with ECT, current methods of administering shock therapy reduce some of the previous risks. Patients now receive a muscle relaxant and general anesthetic prior to treatment. Research has discovered that by placing the electrodes on the same side of the head, memory loss is minimized. It should be noted that continued depression itself affects memory loss.

We all occasionally feel depressed, so perhaps it is difficult to understand why ECT becomes necessary. Amending a malfunction of the brain with a jolt of electricity may seem extreme, but for a family watching the degradation of a loved one, is it not better to kick him in the head than to give him up for lost?

Alannah Regan
Victoria, B.C.

Legitimate feelings

I am presently taking a fourth year seminar course at Carleton University on Women and Health. It is taught by Monique Begin, former Minister of Health and Welfare. Through this course I have become aware of your publication and through it, of the fact that my life experiences with regard to the medical profession are not unusual to other women's experiences.

The Winter, 1983 issue (on *Politics of the Womb*) legitimized my feelings of hurt,

horror, fear, rage and confusion that I have internalized over 23 years. I only wish I had become aware of *Healthsharing* sooner. Please send me a year's subscription.

M. MacMillan
Kanata, Ont.

Hysterectomy Information

Before Christmas I got your magazine and I was so excited I just devoured it. I've struggled for years with hormones, migraines and changes, since I had a hysterectomy in 1970 at 22 years old due to an early I.U.D. What a wonderful gift this sample copy is! I am sending in a subscription to *Healthsharing* for myself and for a friend who recently had a hysterectomy and needs lots of info and connection with other women. *Healthsharing* is a very good magazine, I have not seen anything to equal it here.

Linell Juliet
Boulder, Colorado

Reader donates back issues

A friend gave me this subscription to *Healthsharing* last year and I've enjoyed the magazine very much. I am donating my old issues to public waiting rooms to hopefully make others aware of your publication. Congratulations on a fine magazine.

Dianne Spandier
Dawson City, Yukon Territory

Mini-library winner

I was delighted to receive the mini-library as winner of the *Healthsharing* contest. [Ed. note: This was a draw held among those keen enough to send in a subscription renewal at their first notice in fall 1986.] The books are not only great to have but are also helpful in my teaching and research work especially *The Healthsharing Book*. Also, I have found that your magazine helps me to keep up with current issues concerning women's health issues.

Barry Edginton
Winnipeg, Manitoba

Our Cover Photo . . .

Healthsharing

BREAST CANCER IN THE '80s

Treatment

Reconstruction

Why we fear it

Tricks to using prescription drugs

When women can't read

Hazards of respect for men



Jean MacLea Machell appears on our cover as she looked in 1940 at age 39, five years after her first mastectomy. Her second mastectomy in 1970 was followed by lung cancer in 1985.

Jean McLean Machell (the grandmother of Alice Grange, a member of Women Healthsharing) died of cancer on March 22, 1987.

UPDATE

CVS questioned

Northern transition houses

Until late last year, the Northwest Territories had no shelters for battered women and children. Women living in the far north had minimal social services to rely upon. This is changing. Two transition houses, each with a six-week maximum length of stay, have opened their doors for northern women and children.

The Yellowknife YWCA opened a transition house in September, 1986. As of early April, it had provided shelter for approximately 70 women and 110 children. The shelter, funded by the N.W.T. Department of Social Services, provides housing, support and maintains a crisis telephone line.

The newer of the two houses is Nutaraq's Place. Run by the Baffin Regional Agvvik Society in Iqaluit (a.k.a. Frobisher Bay), it opened on March 2, 1987. "It's called Nutaraq's Place in honour of Leah Nutaraq," Susan Sammons of the Agvvik Society told *Healthsharing*, "She's a 110 year-old resident of the area. Leah has been concerned about spousal abuse for most of her life." Services are offered in English, French and Inuktituk for women of the eastern Arctic.

Another transition house is planned for Rankin Inlet. Safe houses will be opened soon in smaller communities such as Fort Rae.

Alice Grange

Chorionic villi sampling (CVS) is a relatively new test for birth defects. It is described as "no riskier than amniocentesis and just as accurate."

The method samples cells from the chorionic villi, tiny vascular projections on the outer membrane surrounding the embryo. The cells are removed by aspiration or biopsy via the cervix or through the abdomen and are tested in a laboratory for genetic disorder.

CVS is being promoted because it enables the detection of chromosomal and other fetal anomalies as early as eight weeks gestation. But recent articles in the *Canadian Medical Association Journal*, *The Lancet*, and *Resources for Feminist Research* point to the need for widespread, systematic, randomized trials to evaluate the safety and accuracy of CVS before it is made widely available. Such trials are currently underway in the U.K., the U.S., Denmark and Canada. (See Update, Summer 1986)

Concerns about CVS include: false positive diagnoses,

increased risk of miscarriage, introduction of infection into the uterus, fetal growth retardation and the risk of exposing the fetus to an unusually large amount of ultrasound early in pregnancy. The potential use of CVS as a screening tool is being questioned because many of the fetuses with chromosomal anomalies detected by the tenth week will spontaneously abort on their own. It is estimated that as many as 56 per cent of pregnancy losses occur without women being aware that conception has occurred.

In the U.K. consumer groups have had input into the information given to women participating in the trials. However, research has yet to be designed which involves women at the earlier stages of technology development where women can ask if this is a procedure we want to develop. CVS is a prenatal technology of potential concern for all pregnant women.

Dianne Patychuk

Disabled women often abused

Disabled women are more likely to be the victims of violent assault than non-disabled women according to a recent study by Joanne Doucette, a member of the Toronto chapter of the DisAbled Women's Network (DAWN).

Disabled girls are particularly vulnerable. Almost half of the disabled women reported that they'd been sexually assaulted as children as compared to a third of non-disabled women; 67 per cent had been battered by other children. In the vast majority of cases, the assailant

was well known to the child, usually a family member.

Thirty-three per cent of the disabled women reported that they have been battered as adults as compared to 22 per cent of the non-disabled. One in four had been sexually assaulted.

The sample population was self-selected from women attending two feminist conferences in Ontario during late 1986. Questionnaires asked about background, child physical and sexual abuse, adult physical and sexual abuse, medical assault and included space for comments.

Thirty disabled women and 32 non-disabled women comprised the study.

The study, funded by the Ontario Ministry of Community and Social Services, was undertaken after violence was prioritized at a 1985 organizing meeting to establish DAWN. Virtually no information had been published in the academic or popular press. "This is just the first study of its kind in Canada," Doucette told *Healthsharing*, "More research is clearly called for."

The report, released at a Toronto press conference on

April 13th, calls this study a "first step or a sign post, pointing at a problem and a challenge." With over a million disabled women in Canada, programs and services recognizing the violence they experience must be developed. At the present time, most services for victims of violence are not in any way accessible to disabled women.

WHS

Infertility treatment and choices

In Newfoundland one in six couples have difficulty getting pregnant. Infertility is often a hidden, undiscussed problem and this prevents couples from getting information that could help them. Specialized care for infertility is only available in a few larger centres in Newfoundland which puts the largely rural population of the province at a disadvantage. Because infertility has numerous causes and can be a problem for either the male or female, precise diagnosis is often difficult and time-consuming. Whatever the cause, most infertile couples have these things in common: stress in their relationship and feelings of isolation in their search to determine the cause and solution for their infertility.

Approximately 50 per cent of couples respond to treatment for infertility and eventually are able to get pregnant and have a baby. Those couples who do not respond, or have a type of infertility that

currently has no treatment, have more choices than ever before. However choices are not always easy to make. All have problems — some only help couples with certain types of infertility, others are too expensive or are unacceptable emotionally, and some involve a long waiting period. Adoption is becoming increasingly more difficult all across Canada. Because the number of children available to adopt has dropped dramatically in recent years, couples can now expect to wait three to five years from the time they submit their application, to the time they receive their child. Procedures such as artificial insemination by donar and in-vitro fertilization are not available in the province. With the added cost of travel, couples can expect to pay \$500 per insemination attempt, and 3,500 per IVF attempt. Both procedures offer a 10 to 15 per cent chance of pregnancy.

Many Newfoundland couples do not have the information that would help them make decisions about infertility treatments and choices. Because most of us assume from a very young age that we will be able to have children whenever we choose, it can be very difficult to readjust thinking towards being nonparents (not having children) or raising nonbiological children (adopting or having artificial insemination). Planned Parenthood's project *Infertility Treatment and Choices* addresses the need for public information about infertility and its treatment in this province. Six booklets researched and published by Planned Parenthood are being distributed across the province. The project is funded by the Health Promotions Branch of Health and Welfare Canada. Public information sessions are being held in Clarenville, Marystown, Gander, Grand Falls, Corner Brook, Stephenville, Labrador City and Goose Bay from March to June.

DEBORAH REDFERN

Fetal rights

At the beginning of April, a 38-week old fetus became the first fetus to be made a ward of the state. The Belleville, Ontario Children's Aid Society sought and obtained wardship because a pregnant woman refused to seek medical services. The woman purportedly intended to give birth in the parking garage where she made her home.

At the time of going to press, the woman had not yet given birth and legal mechanisms to enforce the court order had not been clarified. Regardless of the specific outcome in this case, the precedent opens the

door to increased legal interference in the area of pregnancy and birth. The court decision gives the fetus protection previously only granted to children. Will this ruling set a precedent to deny abortion to teenaged women or to require amniocentesis or abortion of fetuses with known disabilities? Presumably concepts of abuse could be broadened to take action against women who endanger a fetus by drinking alcohol or smoking while pregnant.

WHS

Baby M

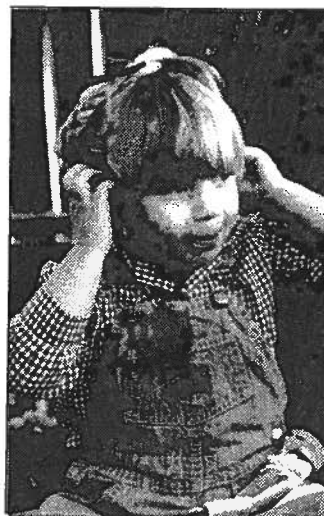
The controversial U.S. legal battle to gain custody of Baby M ended with full custody being granted to William and Betsy Stern. Mary Beth Whitehead, the biological mother of the so-called Baby M who had agreed to be a surrogate mother for William Stern, was not given rights.

The battle allowed public scrutiny of the surrogate parenting contract involved. Whitehead agreed to accept \$10,000 for biologically mothering and carrying through pregnancy a child fathered by Stern. He had the right to demand certain medical care, for instance amniocentesis (which Whitehead had over her doctor's objections) or abortion. If she miscarried prior to four months she would receive no fee at all. The contract did not oblige Stern to accept the baby or to pay if he refused the baby.

Canadian media coverage ignored many details during trial coverage. Both the Sterns are fertile; they did not try to conceive their own child. Prior to marrying William, Betsy Stern had made it clear she did not want a child. They had not explored adoption. Betsy Stern's mild multiple sclerosis, according to MS Society medical advisors who testified on behalf of Whitehead, would have been unlikely to be affected by pregnancy or birth.

Clearly, if this case is any indication, misuse or abuse is part of surrogate parenting arrangements. Journalist Michele Landsberg, in a column in April 14's *Globe and Mail*, joined numerous legal experts in condemning the ruling and calling upon legislatures to rule such contracts unenforceable.

WHS



B.C. update

The B.C. Coalition for Abortion Clinics founded in January of this year has dominated the Vancouver women's health arena in recent months. The Coalition's founding meeting on January 26th drew over 200 active and ardent feminists, health care and community workers. Discussion was thoughtful, lively and produced a comprehensive basis of unity which calls for the Coalition to "seek the establishment of reproductive health clinics throughout the province, that include abortion services, and that are funded by provincial health insurance and that in the interim we establish and support the ongoing operation of an abortion clinic in Vancouver." Open general meetings will be held every three months, the latest held on March 22.

Hot on the heels of the March 22nd meeting the long-awaited Provincial Government report on *The Prevention and Handling of Unwanted Pregnancies* was released. The report, commissioned by B.C. Premier Vander Zalm in December of last year, has reiterated points pro-choice activists have made for years: that access to abortion services is declining; that there are gross inconsistencies in the way therapeutic abortion committees work; and that the provincial government has had no systematic birth control education programme. Vander Zalm and anti-choice activists have reacted harshly to the report, calling it a waste of taxpayers' money. Reports only make a difference to peoples lives when recommendations are implemented; British Columbians will have to wait before we know how the government will act.

Also in March the Vancouver Women's Health Collective and the National Film Board

co-sponsored a premiere of Haida Paul's *Is it Hot in Here?* (reviewed in *Winter, 1986*). The film takes a sensitive and sometimes humorous look at menopause by following individual women's experience. The over 200 people at the premiere were informed and entertained. Inevitably the pro's and con's of estrogen replacement therapy became a big issue in the discussion. Women who came unaware of options to estrogen replacement, left knowing there are choices.

Since October, two women hired through the Vancouver Women's Health Collective have developed an Immigrant Women's Health Committee. The working committee, made up of public health workers, community workers and interested individuals is addressing the needs of the Spanish and Chinese communities. Papers on birth control, Pap smears, sexually transmitted diseases and mental health have been the focus of the committee's work. The papers will be translated into Spanish and Chinese (and hopefully other languages) and made available. Virtually no prior attention has been paid to the health needs of immigrant women in British Columbia. Resources available up until now have been shamefully limited and poorly presented. The small Secretary of State grant funding the Immigrant Women's Health Committee is opening the eyes of those who hadn't recognized the particular needs of immigrant communities. The work will undoubtedly have to continue and expand.

MAGGIE THOMPSON

Northern Ontario report

The Northwestern Ontario Women's Health Information Network (N.W.O.W.H.I.N.) is a non-profit, charitable organization that formed out of the Northwestern Ontario Women's Health Education Project. The group supports and promotes women's health activities in this region. WHIN has been quite active in the year since the project ended. Last fall, we hosted a major women's health conference. As a follow-up to this, we are planning mini-conferences in three outlying communities — Nipigon, Marathon, and Kenora — during May and June. They are planned and organized by local women themselves with WHIN providing advice and funding through a Secretary of State grant.

Women in other small communities have already put on Women's Health workshops. The Red Lake Women's Information Group did a series


of workshops over five weeks using the WHIN kits as a basis. In early April, two WHIN members travelled to Sioux Lookout to present workshops on PMS, DES and menopause to an enthusiastic group of women. Other WHIN members have done numerous individual workshops in various communities.

A major task at this time is the completion of workshop kits which will be distributed to area libraries. When we are finished, there will be eighteen workshop kits on women's health issues including topics such as PMS, stress, nutrition, and patient's rights. For further information, please contact Northwestern Ontario Women's Health Information Network, 8A N. Cumberland St., Suite 17, Thunder Bay, Ont. P7A 4L1 (807-345-1410).

HEATHER WOODBECK
AND JUDI VINNI

Atlantis

**A WOMEN'S STUDIES JOURNAL
REVUE D'ETUDES SUR LA FEMME**



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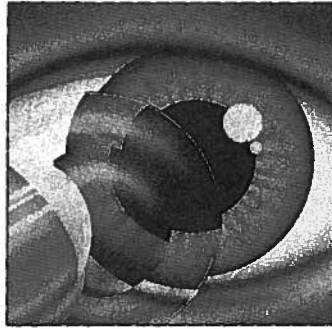
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Contact lens and drug interactions

Eye irritation may occur for contact lens wearers who use certain drugs or lens cleaning solutions or who smoke. Oral contraceptives, for instance, can cause increased sensitivity to the lenses, blurred vision or increased light sensitivity among contact lens users.

According to an article in the February *Canadian Pharmaceutical Journal*, estrogen (contained in oral contraceptives) has fluid retaining properties thought to cause lid and corneal swelling. Tear composition is also altered, decreasing the lubricating ability of the tears. A stickier mucus is produced which may deposit on the lens and result in allergic conjunctivitis and blurred vision. David Wing and Kenneth Gellatly, the article authors, suggest reducing wear time during the first three months of pill use and cleaning lenses thoroughly to make a "successful transition" to



combined use of contact lenses and oral contraceptives.

Other drugs may also cause eye irritation. Sedatives, hypnotics and antihistamines can reduce blink rate in some individuals, which in turn reduces hydration of the lenses. Muscle relaxants may result in incomplete blinking by causing droopy eye lids. Some anti-depressants and diuretics may decrease tear volume. This can lead to corneal drying with hard lenses or lens deposits and irritation among wearers of

soft lenses. Locally administered eye medications may discolour lenses, or alter tear composition. Some eye medications may be absorbed differently by lens wearers.

Specific ingredients in lens cleaning solutions may cause eye irritation. Thimerosal, a widely used preservative in soft contact lens solutions, has been linked to mild 'red eye' in several studies. Individuals experiencing Thimerosal reaction should consult with their practitioner about switching to other cleaning solutions. The lenses themselves will need to be treated by the practitioner to clear them of Thimerosal.

"To ensure that patients obtain maximum benefit from their contact lenses," the authors say, "lens practitioners and pharmacists should be aware of the potential effects of medications taken." However, it is estimated that 50 per cent of adverse contact lens reactions are associated with poor cleaning and care habits. If you're one of the more than 20 million contact lens wearers in North America, check with your health practitioners about drug interactions and find out if you are caring for your lenses properly.

BONNIE LAFAVE

Drugs causing hip fractures

Hip fracture is a leading cause of illness and death in the elderly, particularly women, whose bones tend to be more brittle from osteoporosis. A recent study in *The New England Journal of Medicine* found that the risk of falling and breaking a hip was much higher in those individuals over the age of 65 who were taking certain prescription medications. Tranquilizers and tricyclic anti-depressants that take up to 24 hours to be eliminated from the body were associated with an increased risk of hip fracture. Included in this group are anti-anxiety

drugs such as Librium, Valium, and Dalmane. The lasting sedative effects of these medications can result in lack of coordination or a sudden drop in blood pressure with resultant dizziness upon standing, either of which could precipitate a fall. If the drug is discontinued the risk of fracture is no higher than in those who never took the medication. Shorter acting tranquilizers such as chloral hydrate were not associated with any increased risk.

WHS

Psychological effects of breast cancer surgery

Two years ago a landmark study by the National Cancer Institute in the U.S. showed that the survival rate for women given a mastectomy was no different from those given a lumpectomy plus radiation therapy. However, psychologically there may be differences. *Healthfacts* reports a British study of 101 women which found that 33 per cent of those who had a mastectomy suffered from anxiety or depression. Surprisingly, 38 per cent of those who had a lumpectomy also suffered from the same symptoms. Apparently these women were concerned that the operation may not have removed all the cancer and that it might return. The findings point to a need to offer postoperative counselling to conservatively treated women.

A more positive outlook comes from an American study also reported in *Healthfacts*, in which 54 women were interviewed one year after surgery: 22 had undergone a mastectomy; 20 opted for lumpectomy against their physician's advice; 12 had lumpectomy at the recommendation of their doctor. All the women who opted for the breast-sparing procedure, with or against their physician's advice, said they would make the same choice again. Fifty per cent of those who had mastectomies said that given the choice to-day, they would have a lumpectomy.

WHS

D'Arcy McKillop Farlow

Achieving Health for All

The Epp Report

Thirteen years ago, when inflation reared its head and medicare costs appeared burdensome, Marc Lalonde, then Minister of Health and Welfare, ushered in the concept of health promotion. Hailed internationally as a landmark document, the Lalonde Report neatly equated health promotion with healthy lifestyles. Although the Lalonde Report developed a model that acknowledged environment as a health determinant, its recommended health promotion strategy focused exclusively on mechanisms to encourage individuals and organizations to "accept more responsibility and be more active in matters affecting mental and physical health."

The document's artificial separation of lifestyle problems from structural causes of ill health placed responsibility for health problems entirely on the individual. Health promotion funding was established to produce brochures and advertisements exhorting people to mend their ways by smoking less, running more, controlling obesity, reducing stress levels and generally leading a life of "Participation." It was hoped such exhortations would reduce the use of expensive medical services. Thus health promotion at the federal and provincial levels, relying heavily on guilt and victim blaming, went on a crusade to stamp out undesirable, illness-producing behaviours.

In October, 1986 at an international meeting about health promotion sponsored by Health and Welfare Canada and the World Health Organization, the government released a new document. Jake Epp, Minister of Health and Welfare, is disseminating the new

document, *Achieving Health for All*, to community groups, provincial governments and professionals across the country. At first glance, it is encouraging to note that Health and Welfare Canada seems to be joining those who argue for a dynamic approach to health promotion, one that recognizes the complex relationship between an individual and her or his social, economic and political context.

Does the report stand up on closer scrutiny? The report does acknowledge that our reliance on posters and pamphlets has produced only "slight and slow" behaviour shifts. As a framework for health promotion, the report endorses the World Health Organization's definition of health promotion: "Health promotion is the process of enabling people to increase control over, and to improve, their health . . . Health promotion represents a mediating strategy between people and their environments . . ."

The framework of the report sets out three challenges, three mechanisms and three strategies seen as intrinsic in achieving comprehensive health promotion.

Challenges identified are: to reduce economic inequities; to prevent (through public health measures and lifestyle changes) factors causing ill health; and to enhance people's ability to cope with "chronic conditions" and mental health problems. Not bad, but the challenges presented are not adequately linked to the means and strategies presented later in the report. The report cites the existence of economic disparities and recognizes women as

among "the groups for whom 'longer life but worsening health' is a stark reality"; it does not document specific issues related to economic inequity such as occupational health hazards, chronic unemployment, homelessness and malnutrition.

The emphasis on *coping* contradicts the notion of empowerment (changing or enhancing) implicit in the WHO definition of health promotion. Furthermore, the Epp document suggests that women are in special need of assistance in coping because women are more vulnerable to stress. To support the concept of great stress in the lives of women, Epp cites "women being prescribed tranquilizers and anti-depressants more than twice as often as men [as] a telling sign of the emotional strain women are experiencing."

This ignores other factors affecting prescription patterns. In a well known study conducted by the late Ruth Cooperstock, doctors were found to prescribe more tranquilizers to women than they did to men even when men presented identical symptoms of depression, crying and anxiety. The men were sent to the laboratory for tests or offered physiotherapy, while women were given a prescription. This reflects, not just sexual discrimination in physicians' prescribing patterns, but a whole social attitude towards women's illnesses.

Women will also need support coping with their role as informal caregivers, according to the report. Once again, assumptions deserve to be challenged. With more than 50 per cent of women of all ages in the work force,

society cannot rely on unpaid female labour to care for the ill and elderly in the home setting. Women who are in the role of full-time, lay caregivers are looking for supports and choices that will provide some control over their lives. How does the new framework for health promotion propose to help create control for these women?

Mechanisms identified are: self-care, mutual aid, health environments. Self-care refers to the daily actions taken by an individual to maintain health. Mutual aid encompasses social support networks and groups which enable people to "live interdependently within a community while still maintaining their independence." Healthy environments are not defined; instead the document claims that environmental change is a complex task and leaves the reader to ponder how such change could be accomplished.

Self-care can be a positive, empowering action for the *individual*. However, the document's over emphasis on individual self-care without recognition of the polluted society within which we live undercuts the value of self-care models. The focus on individual wellness deflects attention away from environmental and socio-economic causes of ill-health; it pushes people to assume impossible levels of individual responsibility without recognizing that they have decreasing control over the environment in which they live.

It is the women's health movement that has linked self-help (what the government calls mutual aid) to empowerment through political action. With the self-help groups that originated in the late 1960s and early 70s, women discovered that self-help can generate broad social changes inside and outside the health system. The health care system was recognized as only one example of an institution of social control; thus, for change to occur, structural changes must occur at the system level. By integrating self-help within larger social change struggles, the women's health movement has spurred on other movements to adopt the concept that 'the personal is political.'

Strategies identified are: fostering public participation such that people can "act in ways that preserve or improve their health;" strengthening

community health services; and coordinating healthy public policy.

Again the emphasis is on fostering public participation to enhance "people's capacity to cope." The document acknowledges the need for more money to be allocated to community health services and promotes the notion of community involvement in planning such services; it does not recognize that the goal of community health services and involvement should be empowerment and control. Instead, the goal is simply to strengthen links between communities and services.

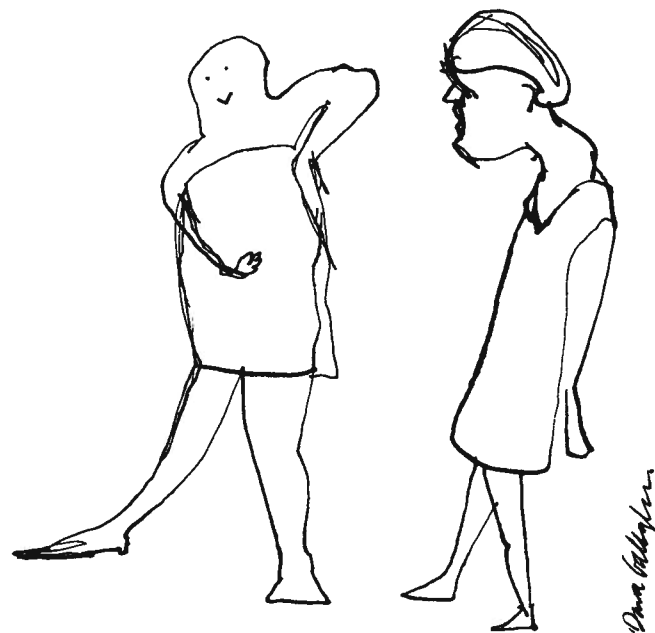
Coordinating healthy public policy, the third strategy, is a laudable goal, but the document provides no ideas as to how this could ever be achieved. Would, for instance, ministries of health become watch dogs of public health, assuming a pro-active role in monitoring health-damaging practices enacted by other branches of government and by the private sector? Or would we all just carry on *coping* as best we can?

What then does the document offer? Does the document indicate forward movement or are we bound forever to live out the legacy of the Lalonde Report by focusing on individual respon-

sibility instead of advocating for broad-based social change to alter structural determinants of ill health? The content of the Epp document makes it clear that we have barely begun to develop concrete strategies to address socio-environmental health concerns and to reduce inequities and barriers that contribute to ill health. The report's positive rhetoric cannot disguise this fact.

Even so, the report does offer value. It indicates at least some movement on the part of the government to incorporate health promotion into overall health strategies. It may provide a stepping stone to increasing budgets for health promotion activities. Certainly, it provides us, the public concerned about health issues, with a tool to pressure the government to continue in the direction implied by the release of the report. Within the document we find a clearly stated support for the goals and activities of Canada's women's health movement and we should use the Epp report to substantiate our position at the leading edge of health promotion.

D'Arcy McKillop Farlow is a community health educator and researcher presently living in Waterloo, Ont.



"I dunno Patty, it strikes me that towel-wrapping isn't really an aerobic exercise."

If You Have Breast Cancer ...

Connie Clement

Finding a breast lump is, for most women, one of the most frightening discoveries possible. Knowing that only about two lumps out of 10 will prove to contain cancer cells does not really begin to dispel the panic and anxiety women feel upon discovering a breast lump. It is fear of cancer that makes many women avoid doing breast self-examinations or, having discovered a lump, avoid touching their breasts. One of the best ways to reduce fear is for women to pay attention to their breasts and learn how to do breast self-examination.* If lumps get larger and smaller according to the pattern of a woman's menstrual cycle it's a good indication that the lumps are noncancerous (also called benign) and are most likely what is called fibrocystic disease.

All newly discovered breast lumps, regardless of size, should be examined by a health care practitioner because of their potential to be cancerous. Other breast changes concurrent with a lump may indicate greater likelihood of cancer. These include discharge from the nipple (clear, milky or bloody), and puckering or changes in

**Nearly 90 per cent of breast lumps are found by women or their partners, either in the course of daily life or by performing breast self-examination (BSE). Information about BSE, the most important breast health screening technique, is readily available in the books mentioned in this article or from any chapter of the Canadian Cancer Society, your public health department, hospitals or women's health groups.*

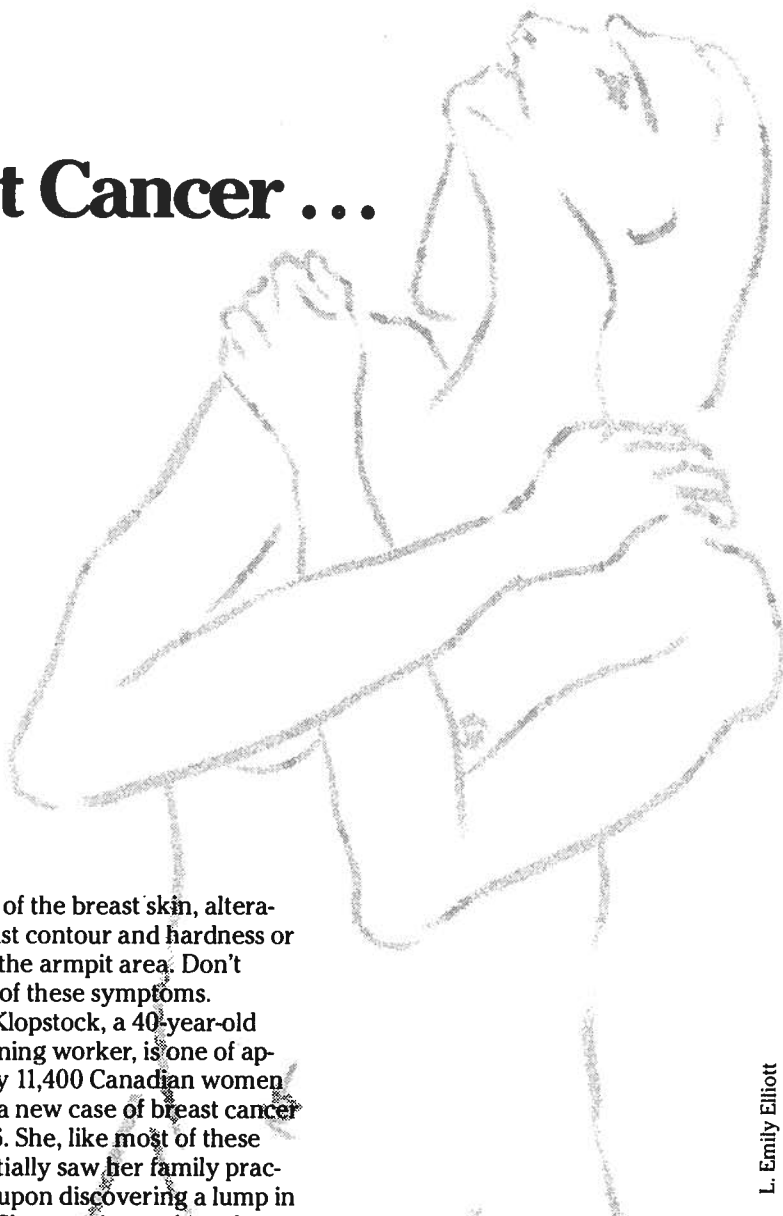
the texture of the breast skin, alteration in breast contour and hardness or swelling in the armpit area. Don't ignore any of these symptoms.

Carolyn Klopstock, a 40-year-old family planning worker, is one of approximately 11,400 Canadian women treated for a new case of breast cancer during 1986. She, like most of these women, initially saw her family practice doctor upon discovering a lump in her breast. She was then referred to a specialist. Carolyn was lucky enough to be referred to a top notch surgeon with an interest in breast cancer treatment. Not all women will be so lucky. Women in large urban centres may have the option of consulting a oncologist (cancer specialist); women in most Canadian communities will consult surgeons, and in many communities the only available general surgeon may have little breast cancer treatment in their practice.

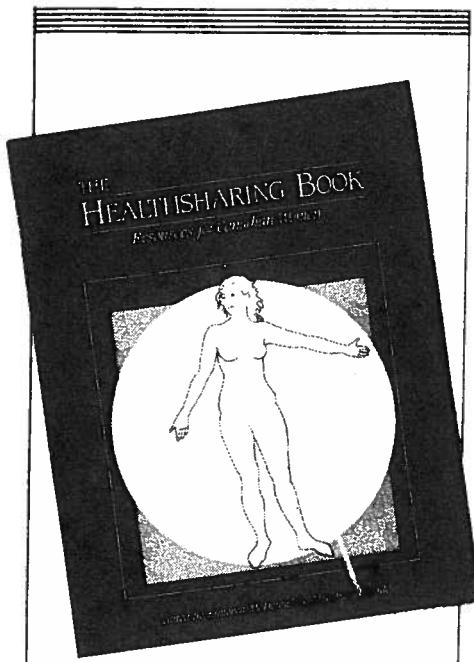
Finding a good surgeon or cancer specialist is important. The specialist's experience, concept of disease spread and knowledge of current research findings will affect the treatment recommended. Physicians who are out-of-date with new research results are

more likely to overtreat than doctors who do more breast treatment. If you find yourself seeking diagnosis or treatment for breast problems and have any doubt about your doctor's recommendations, try to obtain another opinion.

Carolyn's surgeon took time to talk when he first met her. He first took an extensive oral history, including questions about her breasts and this lump, personal and family history of breast conditions, cancer and in particular breast cancer. The surgeon then talked with her about various types of breast cancer. Then he physically examined her breasts and nipples and felt her armpits and the base of her neck for enlarged lymph glands.



L. Emily Elliott



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from Healthsharing Magazine

A must for every woman, library and resource centre, this guide includes articles, annotated listings of organizations across Canada, bibliographies of reading matter, and audio-visual materials. Subjects covered are childbearing, aging, eating disorders, drug and alcohol abuse, fertility, sexuality, therapy, violence, menstruation, menopause, occupational and environmental health, cancer, DES and disabled women.

Edited by
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&
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Non-invasive diagnostic tests

There are several non-invasive tests that may be used to help in the determination of cancer. Most common and most useful is the mammogram (breast X-ray). The advantage of a mammogram is that an invasive test is avoided; the disadvantage is exposure to radiation. Mammograms are controversial because of their use in *routine* screening for breast cancer in women with no symptoms. They have been used to screen women because they can detect lumps too tiny to be felt — as much as two years earlier than by manual examination. Routine use appears to be beneficial for women over 50, but studies don't yet show benefit for younger women.

Mammography *can* provide useful information about lumps when a diagnosis is needed. If you find yourself in the situation of being referred for a mammogram, ask what your physician expects to learn from the mammogram and confirm that its benefits outweigh the cancer-causing risk of radiation in your case.

The equipment may also vary in the mechanisms used. X-rays use photography-like equipment and a woman's breasts are pressed against a photographic plate to obtain an image. Both the metal plate which touches a woman's breasts and the room will be cold. "Take a wool bathrobe, socks, a shawl!" laughs Carolyn.

For some women who have large breasts or particularly dense or glandular breasts, mammogram results may be difficult to interpret. Several other techniques also create a visual image of breast tissue. None are as common as mammography, each has advantages and disadvantages depending upon breast size and other factors, and some are still fairly experimental. If another technique is recommended try to find out more about it, how much it's been used and your doctor's experiences with it.

Diagnostic biopsies

Depending upon the lump found and the cancer specialist consulted, visual techniques such as mammography or ultrasound may be by-passed or followed by a biopsy. A biopsy is the removal and examination of tissue for diagnostic purposes.

The simplest biopsy, a needle biopsy, can be performed in a doctor's office. Most breast lumps are fluid-filled cysts. If a cyst is suspected and cancer seems unlikely, a needle biopsy to aspirate fluid and perhaps tissue may be a suitable first test. The physician inserts a very thin needle; if the lump is a fluid-filled cyst, the fluid is withdrawn and the cyst collapses. A simple fluid-filled cyst, in most cases, will not be cancerous and treatment is completed at this stage.

In many cases cells can also be withdrawn using a fine needle. The cells can then be sent to a cytology laboratory to be tested to see if any cancer cells are in the sample. Cytology is the study of cells and not all labs can do cellular analysis; thus, this analysis is only possible if a woman and her doctor have access to cytology facilities.

The other common type of biopsy is a surgical biopsy. Going for surgical biopsy does not mean a woman has cancer, it just means that other methods have not yet ruled out cancer.

Surgical biopsies are either incisional (removing only a portion of a lump) or excisional (removing the entire lump). A surgical biopsy may be done in a doctor's office with local anesthetic, but is most often done in hospital using general anesthetic. Some women prefer to be anesthetized and not aware of the surgery and some prefer being awake. If you need a surgical biopsy let your doctor know your preference. Before the biopsy talk with the surgeon about the cut lines to be used (sometimes the scar can be less visible by cutting under the breast or arm).

You'll also need to decide with your surgeon whether you give any permission in advance for further surgery at the time of the biopsy. Standard practice up until approximately a decade ago, was that a woman was anesthetized without knowing if she would wake up with or without her breasts. The biopsy section would be sent to the hospital lab and if cancer was found the woman was operated on within the hour. In most cases today a 'two-step' procedure is used, whereby the surgical biopsy is performed separately from major breast surgery. Rose Kushner, a member of the American National Cancer Advisory Board and author of *Alternatives* is largely responsible for the implementation of

the two-step procedure. Separating biopsy and surgery allows a woman the option of being involved in the choice of treatment and gives her time to prepare emotionally and physically for the surgery.

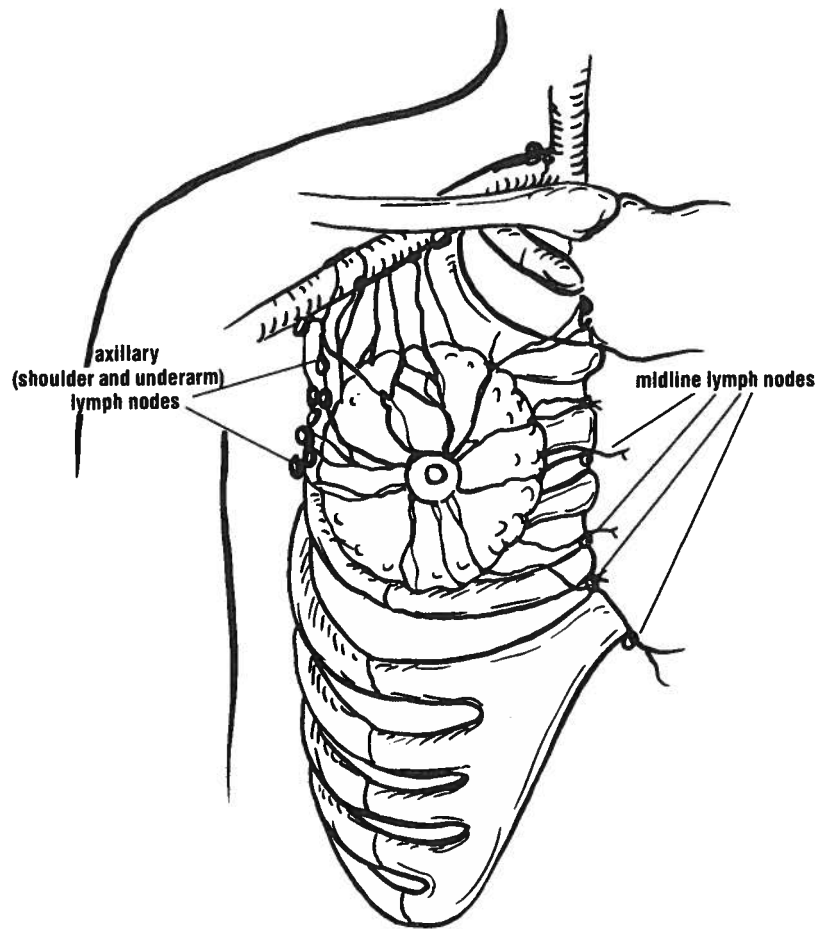
When the biopsy is performed the tissue sample should be tested for hormone dependency. Less than half of all breast cancers appear to grow faster in the presence of estrogen. Testing for this is important so that if a woman has estrogen dependent cancer, the benefits of hormone therapy can be weighed.

Treatment options

A British review of randomized early breast cancer trials around the world (published in *The Lancet*, 1984) found that for women with similar sized small lumps there is no significant correlation between the length of time they lived after breast cancer surgery and the type of surgery. Today the responsible approach to breast surgery is to remove no more than is necessary to remove the cancer. The radical mastectomy of yesteryears has been replaced with several types of less invasive and less mutilating surgery.

Factors which will affect the type of surgery recommended include the size of the lump itself, its position in the breast, whether or not the lump is attached to the ribs or skin, final cosmetic appearance and the type of cancer. Between the biopsy and the surgery, some women, depending upon the preliminary assessment, will have had extensive tests to find out if the cancer has already spread to other parts of the body (e.g. blood tests, liver and bone scans). These tests should be done only *after* a biopsy indicates cancer.

Due to the wide number of surgical techniques, it is important that a woman knows the extent of surgery prior to its being carried out, and has been involved with, and is accepting of, the rationale behind the choice of surgery. If you are diagnosed with breast cancer be sure to ask a health care practitioner to explain the reason for any recommended treatment. You should be able to understand both possible adverse effects of treatment and possible consequences of not taking the treatment. Any woman considering breast reconstruction should have a referral to a plastic



Lymph nodes associated with the breast.

Susan Leopold

surgeon before her surgery to ensure that enough skin remains to allow later reconstruction.

Whatever type of breast surgery is performed, a few lymph nodes are often removed from the armpit. Depending on the surgery a single incision or two separate incisions will be needed to remove breast tissue and lymph nodes. The removal of lymph nodes is diagnostic; the nodes will be tested to find out if cancer has spread to the nodes. This information will be used to decide whether or not postoperative radiation or chemotherapy might be beneficial.

The basic types of surgery are listed here in order from least disfiguring to most:

Lumpectomy, local excision or tylectomy removes the lump itself and minimal surrounding tissue. Depending upon the size of the lump and the size of the breast, the final cosmetic result may show only minimal scarring and changes in breast contour.

Partial or segmental mastectomy removes the lump and a greater amount of surrounding tissue. The breast is partially saved, but it can be quite disfiguring depending upon

HEALTH WANTED

Birth environments

I am studying social, cultural, medical and environmental/psychological factors that surround birth, with the aim of developing a Canadian model for an alternative birthing centre. I am interested in women's experiences and the medical outcome in the midwife assisted home birth model vs. the doctor managed hospital model. Anyone with any information or interest please contact me. Jo-Ann Lowell, 1230 Church St., Apt. 1, Halifax, N.S. B3J 2E8.

Newsletter about miscarriage

I am interested in contacting individuals interested in a newsletter I want to start about miscarriage. I hope the newsletter can offer information, support, theories, experience and hope for the future.

Anyone interested in writing, offering ideas, collecting research, typing or identifying support groups, please contact me. Write Cathy McDiarmid, c/o Born to Love, 61 — 21 Potsdam Rd., Downsview, Ont. M3N 1N3.

Questionable practice

The active ingredient of Bendectin (an anti-morning sickness drug withdrawn from the Canadian market in 1983) is in several over-the-counter drugs in Canada. Doxylamine, the active ingredient, is found in small quantities in Vicks Formula 44 with DM, Mersyndol with codeine, and Nyquil.

breast size. Often the quarter of the breast that contains the lump is taken out (this is called a quadrantectomy); this tends to be somewhat more disfiguring, depending upon breast size, and is sometimes considered a separate type of breast surgery.

Total or simple mastectomy removes the entire breast tissue, leaving underlying muscle and most of the lymph nodes. This is quite disfiguring and scarring is more extensive than with a lumpectomy or partial, but the sunken chest look of a radical mastectomy is avoided.

Modified radical mastectomy removes the entire breast, a larger portion of armpit lymph nodes and usually some chest muscle. The more chest muscle that is left, the less hollow-looking the chest is following surgery. This method is losing popularity as surgeons turn to less drastic treatments.

Radical mastectomy, the removal of the breast, underlying tissue and muscle and lymph glands is no longer performed. Some of the women who had this disfiguring surgery helped fight for the newer less mutilating surgeries.

The surgery will take place in hospital under general anesthetic. An average stay in hospital is five days plus. Women may experience throat soreness and lethargy from the general anesthetic. The breast operated on may be bruised and painful at first, just as after most major surgery. Painkillers are generally offered. Generally a woman will be discharged after her stitches are removed or else the stitches are removed at her doctor's office. Following discharge from hospital women should watch for elevated temperature, redness or increased tenderness, any of which could indicate a local infection.

Some women have treatment in addition to the surgery. This treatment is generally called adjuvant therapy and can be radiation, chemotherapy or hormone treatment or a combination thereof. There is not yet one standard therapy and several research studies are being conducted in various parts of Canada and other countries to learn more about the best use of these treatments.

If cancer is found in the lymph nodes, radiation therapy is often advised following surgery to kill off any

cancer cells remaining in the intact portion of the breast or armpit. All cells are susceptible to radiation (hence, concerns about unnecessary X-rays), but cells are most susceptible when they are in the final stages of cellular division. Because cancer cells divide more often than normal cells, they are more vulnerable to radiation than healthy cells. Radiation therapy varies from place to place; treatments to the breast five days a week for five weeks postoperative would not be uncommon. Women undergoing radiation may find themselves tired or may experience muscle pain, skin irritation or increased susceptibility to sunburn. During treatment women shouldn't wash with soap, and keeping underarms clean can be problematic. A small number of women may develop scarring or the development of more fibrous tissue in the breast.

If the cancer has already metastasized and spread beyond the lymph nodes, chemotherapy may be recommended depending upon the extent of the spread. Chemotherapy uses anticancer drugs to kill cancer cells that have entered the blood and lymphatic systems. Again the frequency of cellular division by cancer cells makes cancer cells more vulnerable to chemotherapy than ordinary cells, but the anticancer cells affect the entire body. Hair loss, skin flaking and nausea and vomiting are common effects of chemotherapy because hair, skin and gastro-intestinal tract cells also divide frequently. The anticancer drugs are taken by injection or pill, generally weekly or monthly. Usually the dosage is built up until monitoring of white blood cells drops to an established level; then the treatment is slowed or stopped for a period of time. Some of the drugs are highly toxic; some fairly mild. Only premenopausal women have shown improved survival time with chemotherapy.

Women with cancers which grow more rapidly in the presence of estrogen may be advised to take an anti-estrogen drug following surgery. Tamoxifen is the most commonly used anti-estrogen pill; it is thought to compete with estrogen and prevent the normal absorption and utilization of estrogen. It slows down the rate of cancer growth, rather than aiming to kill cancer cells. It is used primarily on postmenopausal women.



Terri Robertson

Recovery and healing

Following surgery most women experience a numbness and lack of sensation in the breast because so many nerve ends are cut during the surgery. For most women the sensation comes back after several months. For some women, the sensation that returns first is pain — pins and needles, short, darting pains that come and go quickly, and aching; other women feel no pain. Use of the arm may be temporarily lessened, even if only a few lymph nodes are removed for diagnosis — this may last from a few to several months affecting reach and how much weight can be carried. For women who have had many lymph nodes removed, swelling (lymphedema; also called milk arm) can be long-term. Wearing an elastic bandage or post-mastectomy sleeve may be necessary to stimulate circulation and decrease swelling. There is no way to predict exactly how a woman will feel postoperatively or how long her healing will take.

Every woman who undergoes breast surgery has to find means to adjust to and accept the changes in her breast or breasts. "If you've never had surgery," says Carolyn, "nothing really

prepares you for looking down and seeing a taxidermy display right there, so close, on your own breast." Kushner writes about what she calls "telescoping," a process whereby as time passes women downplay the trauma of the surgery and the impact of losing a breast. But Kushner has found in her 15 years of talking to women about breast cancer that many don't heal emotionally because there is little social space to talk or create adjustments. Increasingly physicians and therapists are understanding the importance of recreating positive body image and women are learning to support one another through this process.

It's tempting to see the surgery as the end of the breast cancer, to leave it behind and get on with life. Unfortunately, having surgery and even follow-up treatment is no guarantee that breast cancer is cured. Increasingly, breast cancer is being viewed as a chronic or long-term disease. It is important for women to learn symptoms that might indicate a recurrence, to continue medical monitoring, and to make changes in their lives which may influence the likelihood of a recurrence.

"I'm no longer obsessed with dying nine months after my surgery, but it's right up there," Carolyn tells me, "The statistics drive me nuts. According to *Our Bodies, Ourselves* I'm in a category of 62 per cent 5-year survival. The good news is that I can do something about it." Prior to her surgery — booked only two weeks after tentative diagnosis of cancer — Carolyn chose not to read a lot, but to go on instinct and trust her two very good practitioners. She put her pre-operative energy into preparing for surgery by exercis-

ing and improving her diet. Now she is learning more about cancer. She's finding out more about the diet and environmental precursors of cancer and about the relationship between stress and cancer. She's joined a visualization group at a chronic care hospital specializing in cancer treatment. Visualization techniques vary. Carolyn is learning about relaxation techniques and how to visualize increased numbers of white blood cells to combat cancer cells in her body.

Carolyn is one of increasing numbers of Canadian women beginning to speak out about their breast cancer experiences. And women are learning that in spite of whatever they might have done personally to discover the cancer early or in choosing one treatment over another, breast cancer is an immensely complex disease — a disease so fraught with influencing factors that blame can't be placed on any individual action. "I really wanted to find a cause and effect. After a while I realized that one of the reasons I got cancer may be because there is no reason," says Carolyn, "It's not that important what caused it. What's more important is to save myself and, secondly, to contemplate the relationship between visualization, exercise, healing and any further illness treatment I might need."

Connie Clement is a member of Women Healthsharing who lives in Toronto.

Thanks to Margaret Nixon for undertaking some of the research for this article. Margaret Nixon teaches nursing at Camosun Community College in Victoria, B.C.

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Lorna Zabach

Breast Reconstruction

Thanks to recent advances in plastic surgery techniques," a pamphlet on breast reconstruction from the U.S. Department of Health tells us, "a mastectomy need not have the same physical and emotional consequences it had in the past."

Any woman who has had a mastectomy can consider breast reconstruction. Not only are more sophisticated surgical techniques yielding better results, but most medical insurance plans in Canada now cover the cost of the procedure. Breast reconstruction is the rebuilding of a breast contour after the breast has been surgically removed, most often to treat breast cancer.

The first silicon breast implant was designed in 1962. However, because of concerns that the implant might mask symptoms of the recurrence of breast cancer, these early implants were used almost exclusively in breast augmentation. In 1971, Reuven K. Snyderman of New York's Sloan Kettering Cancer Centre, paved the way for modern breast reconstruction by suggesting that silicon implants could be placed under the chest skin that was left after a mastectomy. He demonstrated that the skin was looser and more flexible than had previously been thought and that an implant would not interfere with its blood supply. Today, this procedure — the placing of an implant beneath the chest muscle and/or skin of a woman who has had a simple mastectomy — is common practice in reconstructive surgery. Breast implants consist of a pliable silicon bag filled with silicon gel, or a saline solution, or layers of both. There are varia-

tions in design — shape, size, thickness of the silicon bag — depending on which company produces them.

Some plastic surgeons prefer to gradually stretch the skin by using an inflatable silicon bag as a "tissue expander." The bag is first placed under the chest skin and/or muscle and filled with saline, little by little, over a period of weeks. When the reconstructed breast is about the same size as the remaining breast, the inflatable implant is removed and replaced with a more permanent one. Dr. Richard Warren, a Vancouver plastic surgeon, uses tissue expanders to give the reconstructed breast a softer look. "I inflate the tissue expander until it is slightly larger than the other breast. When I replace it with a smaller silicon implant, the breast settles a little and ends up looking less rounded; there's more of a natural contour."

Why, given the risks and possible complications do women want breast reconstruction?

Even the most skillfully reconstructed breast will never look or feel completely natural and will never exactly match a woman's remaining breast. Some plastic surgeons suggest having the remaining breast altered, either made larger or smaller, or lifted. This procedure often involves the use

of a second implant, a rather extreme measure to achieve symmetry, especially given the fact that most women do not have breasts that match each other naturally.

A woman who chooses to have a nipple added to her reconstructed breast is usually encouraged to wait five to six months for the implant to settle so that the nipple can be placed as accurately as possible. Nipple reconstruction usually involves taking tissue from the woman's labia or from the nipple of her other breast and grafting it on to the reconstructed one.

Until recently, women who had undergone radical mastectomies (that is where the entire breast, the skin and underlying fat, the lymph nodes in the armpit and along the collarbone, and the major and minor pectoral muscles are removed) were considered poor candidates for breast reconstruction because they did not have enough muscle or skin remaining after the operation to stretch over an implant. In 1977, surgeons at Emory University in Atlanta, Georgia developed a procedure called the "latissimus dorsi flap rotation." The latissimus dorsi muscle from the back, along with some skin, is cut out and rotated through a tunnel high in the woman's armpit to the front of her body. This muscle tissue and skin is used to supplement what little remains after a radical mastectomy and enables the surgeon to cover an implant. Not only can the breast mound be rebuilt, but tissue transferred from the back can also be used to fill out the hollow areas beneath the collarbone left by removal of the major pectoral muscle and to

recreate the front fold of the armpit.

Gaining popularity these days is a procedure that involves making a lateral incision across a woman's abdomen, removing tissue and skin from the area between the navel and the pubic hair line. The rectus abdominis muscle is then severed and everything is passed into the breast area through a tunnel under the upper abdominal skin. According to reconstructive surgeons, most women have enough flesh in the abdominal area (!) to eliminate the need for an implant with this procedure. Rectus abdominis transfer may appear attractive to women who have problems with or concerns about silicon implants and still want reconstructive surgery. However, the surgery is long and complicated requiring up to six hours under general anesthetic and tremendous skill on the part of the surgeon. There is usually a good deal of post-operative pain both in the breast and the abdominal area and a woman ends up with two fairly large scars.

There are risks and complications associated with all forms of breast reconstruction. Aside from complications that can result from any form of surgery — problems related to the anesthetic, moderate to severe pain, the development of infection in the area around an incision — there are other potential complications specific to breast reconstruction. Hematoma, a pocket of bloody fluid that results from hemorrhage around the implant (or at the donor site, if tissue is transferred) may need to be surgically drained.

Sloughing can occur. In rare cases, the skin of the chest wall literally peels away and the implant is rejected. According to Rose Kushner, who has written extensively about her experiences with breast cancer and subsequent reconstruction, "sloughing usually occurs if much underlying tissue was removed during the mastectomy itself. Plastic surgeons have devised techniques to avoid the problem by grafting healthy skin to the chest before the implant is inserted."

There is the possibility of tissue death, particularly in procedures where "flaps" (transferred tissue) are used. If the blood supply to the transferred tissue is impaired or is partially insufficient (having diabetes, smoking cigarettes or receiving radiation to the blood vessels in the flap can all de-

crease blood flow to the skin), skin death can result. Although reconstruction can usually be completed with the remaining portion, at least part of the flap can be lost as a source of tissue for reconstruction.

**In our culture,
messages that
a woman
isn't a whole person
without both her
breasts
are extremely strong**

Other risks pertain to the implants themselves. Saline implants appeal to some women, first because they are made with a small valve through which the saline is injected to make the implant larger or smaller, depending on what is desired, and second because saline is known to be compatible with normal body fluids. This is important in the event that the implant leaks. And they do. According to Dr. Pierre Blais, of Medical Devices at the Health Protection Branch in Ottawa, virtually all saline implants eventually deflate, with the contents leaking out into adjoining tissue. The implant has then to be surgically replaced. So much for popularity.

Double lumen implants consist of an inner envelope filled with silicon gel surrounded by an outer envelope inflatable with saline. One supposed advantage of the double lumen design is that the outer saline-filled envelope, although it, too, will deflate in time, may act as a barrier to gel bleeding out from the silicon-filled inner bag.

Silicon implants, although they are the most popular, presumably because they don't deflate, *do* leak. Dr. Thomas L. Dao, chief of Breast Cancer Surgery and Research at Roswell Park Memo-

rial Institute in Buffalo, was first to notice that a silicon implant, when placed on a piece of paper, will leave an oily residue after a day or two. Even though silicon is thought to be inert and nonreactive within the body (silicon implants have been used in breast reconstruction for 20 years), no actual studies looking into the long-term effects of leakage have been done.

One of the most common complications with gel-filled implants is capsular contracture. "The body naturally reacts to the silicon implant (to the bag as well as to its contents) the same as it would to any foreign substance," says Blais. "It surrounds the implant with a protective layer of fibrous tissue. In many cases, this fibrous capsule becomes so hard and thick that it squeezes or contracts the implant into a ball-like shape. The breast, consequently, takes on a hard, rounded, often misshapen appearance and can become very painful." This may occur, although to a lesser degree, with saline filled bags as well.

Individual women react differently to silicon. There is no way of telling to what extent capsular contracture will occur. Regular post-operative massage can help prevent the build up of the capsule. Placing the implant between or beneath layers of muscle seems to decrease the incidence of contracture. According to Dr. Warren, 20 to 35 per cent of women with submuscular implants experience capsular contracture as opposed to 65 per cent of those whose implants are placed under the skin or breast tissue alone. However, there is controversy about the submuscular procedure because, if complications do occur, the implant is much more difficult to get at when it is under the muscle.

Most women who experience capsular contracture do so within five years of reconstructive surgery. Their choices at that point are to do nothing or to have the surgeon squeeze the capsule of fibrous tissue, either manually or by machine, to try to break it up and allow the implant to resume its shape and position. There is, of course, a danger of rupturing the implant with this procedure. A third option is more surgery to remove the capsule and reposition the implant.

Silicon implants *do* rupture. Dr. James Mason, a dermatologist from

Waco, Texas recommends "that women with implants who have had any hard blow to the breast seek immediate medical attention. Any fluid released from a ruptured implant can form a hard, unsightly, possibly inflamed mass requiring surgery. The fluid also has a tendency to travel around the body."

Implants can be defective. Product control in both Canada and the United States is poor (see *One Woman's Story*, following). Defective implants can make their way into doctor's offices and, subsequently, into women's bodies where they can cause serious problems.

Why, given the risks and possible complications, do women want breast reconstruction? Surveys have been conducted, including one by Edward Clifford, a psychologist at Duke University. He found that most women had negative feelings about their bodies after mastectomy. They felt lopsided or unbalanced, they were self-conscious about their appearance. Some experienced strong negative feelings when they viewed themselves in a mirror or while bathing.

Most women I spoke with expressed extreme dissatisfaction with external prostheses (breast forms). One woman who had both her breasts removed in 1963 decided 20 years later to have them reconstructed. "It wasn't until 1982 or so that OHIP began to pay most of the cost. So I decided then to have it done. And despite the fact that my breasts aren't perfect — they aren't what I dreamed they would look like — I am so much more comfortable. Before [the reconstruction] I was in constant misery. The prosthesis kept shifting, once one floated away while I was swimming. They were hot and irritating. Now I don't even think about it."

Sally Thomas, a Los Angeles nursing professor, recently surveyed 102 women after mastectomy to find out why they had not chosen breast reconstruction. Most of their responses centered around fear that the implant would cause cancer or make any recurrence of cancer more difficult to detect. Some dreaded the possibility of more pain or repeated anesthetic while others didn't like the idea of having anything unnatural under their skin.

In our culture, messages that a

woman isn't a whole person without both her breasts are extremely strong. Even women with small breasts or with breasts that don't conform to a specific shape are described in some medical literature as being abnormal. Dr. Hal Bingham, a professor at the University of Florida College of Medicine made this disturbing statement in a 1985 issue of *Midlife Wellness*: "The self-image of an American woman is not complete without her breasts, particularly in our society where significant emphasis is placed on the female chest as portrayed on television, in magazines and in newspapers. We actually worship the female breast and when a woman has a breast removed, she loses one of her more important identifying features. This severely affects *her* body image." [emphasis mine]

With attitudes like these surrounding us, it is not surprising women experience emotional pain and insecurity after mastectomy. Nor is it surprising that women who have their breasts reconstructed express feeling better about themselves afterward.

But poet Audre Lorde, in writing about *her* experiences with mastectomy in *The Cancer Journals*, says: "Society's emphasis on wearing a prosthesis or on breast reconstruction (in short, looking 'normal') after a mastectomy prevents women from coming to terms with their own pain and loss and, in doing so, getting in touch with their own strength."

Women *do* need strength and support to get through breast cancer and mastectomy. For some women breast reconstruction can help in this process, for others it will only mean more physical and emotional stress. A woman considering reconstruction should thoroughly investigate the procedure and talk to other women about their experiences. She needs to weigh the desire to look more symmetrical and "normal" against the risks of undergoing more surgery and possibly serious complications.

Lorna Zabach worked with the Vancouver Women's Health Collective for over five years. She lives in Vancouver.

In October, 1983 Jane Stone (not her real name) had breast surgery involving the insertion of a silicon implant. Two days after surgery, a lump had begun to form in her right breast. Whenever she lay flat and lifted her right arm, she noticed an unsightly bulge where the implant was sitting. She found it uncomfortable, thought that the implant might be too low, but decided, for the time being, to live with it.

By March, 1984 her breast had become extremely uncomfortable and she returned to hospital where the plastic surgeon who had performed the original operation attempted to raise the implant. Recovered, or so she thought, Jane moved to Vancouver where she was enrolled in an industrial baking course. Six months later, she was having difficulty using her arm (a situation that interfered with her work). By now, there was a very large lump in her right breast.

She went to see a second plastic surgeon. He told her that the lump had nothing to do with the implant and asked her about breast cancer in her family. Now she was scared. He sent her to a general surgeon who told her the swelling probably *was* due to the implant either leaking or causing inflammation in her breast. She had three choices: have the implant replaced; try once more to have it repositioned; or have it removed completely. She decided to have it removed and returned to the plastic surgeon who had performed the original surgery.

After the operation, the surgeon phoned her mother with whom Jane was living to report: "Everything went fine," he said, "but it's the strangest thing. All we found in Jane's breast was free-floating silicon. The bag has completely disappeared."

Jane was shocked. She asked where

One Woman's Story

the implant could have gone and was told that it must have been absorbed by her body. "But," the surgeon said, "these bags are made of material totally unabsorbable by the body." He searched her breast for the bag and couldn't find it.

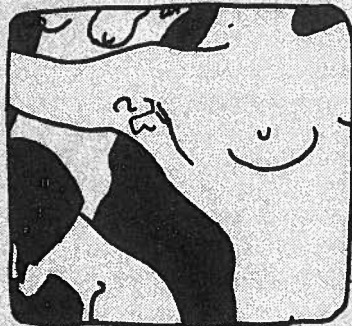
Two weeks later, there was still a lump in Jane's right breast. The plastic surgeon sent her back to the general surgeon who said he'd heard of bags breaking. "When the silicon gel is exposed to tissue it causes lumps and pain such as you are experiencing," but he'd never heard of a bag disappearing completely.

The pain became more and more intense and began moving into her lymph area and down into the muscle of her right arm. By this time, Jane was employed as an industrial baker. But, unable to use her arm effectively, she was forced to leave her job. She went from doctor to doctor trying to find someone who could define the problem for her and tell her what to do.

It was at this point that Jane sought legal advice. Margaret Smyth, a Vancouver lawyer, agreed to take her case. Margaret's first step was to help find another team of surgeons that might give Jane some answers. Jane underwent further examination, mammography, etc., only to be told that the results were inconclusive: "The silicon articles are too minute to be identified as such. It's hard to tell whether what we're seeing is silicon or fibrocystic breast lumps. And then you have all this scar tissue from repeated surgery."

From there, she was referred to a neurologist because of the difficulty in using her arm. Tests were performed and confirmed nerve damage and some loss of function. Another surgeon thought he might be able to remove the major lump in her breast to

give her some relief from the pain. However, when he opened her up, he found the tissue so congealed he could do nothing and reclosed the incision. Jane is now being offered a mastectomy.



They never found the bag. There is a new mass developing in the area of her ribs. Doctors think that, because the implant was originally inserted behind her pectoral muscle, it might have slipped into the rib area after it broke. The bag may have been cut during one of the attempts to position it correctly or it may have been defective in the first place.

Doing research for Jane's case, Margaret Smyth has come across numerous cases (mostly in the United States) in which women have successfully sued manufacturers for damages resulting from ruptured bags. There is a group of plastic surgeons in Toronto suing implant manufacturers for damages to their reputations and for the costs of repeated surgery to correct implant-related problems.

"Medical devices of this type have not been adequately tested or regulated," says Margaret. "In the States, independent testing is required. In Canada, most companies that currently make implants need only have registered their name and the name of their product with the Health Protection Branch. No testing whatsoever has been required before the product

has gone on the market."

The American experience indicates that manufacturers know about implant defects and failure and continue to sell their products anyway. It's apparently cheaper to pay the odd damage claim than it is to improve the product.

"Judging from the number of lawsuits in progress, implant rupture is a real risk associated with this procedure. Responsibility lies with physicians to outline all the risks of a procedure for their patients. My client was apparently told she might experience some hardening in her breast, but that's all!"

Margaret would like to see more women coming forward. She suspects that the number of complaints is very small compared to the number of women who experience problems. "Undergoing breast surgery or breast reconstruction seems to be something women have mixed feelings about. They certainly get mixed messages about how appropriate it is from the rest of society. I think most women are too embarrassed to complain if anything goes wrong."

There have been enough complaints about breast implants recently to alert the Health Protection Branch in Ottawa. A Health and Welfare committee has been struck to study their safety and effectiveness. It will publish a report in the near future.

Further Reading

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Kushner, Rose, *Alternatives: New Developments in the War on Breast Cancer*, Cambridge, Mass., The Kensington Press, 1984.

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HEALTHWISE

Breaking the Prescription Code

Priscilla Cook

You hurry out of the doctor's office, annoyed that you had to wait so long, maybe just a little pleased to learn that you really are sick — it wasn't your imagination. And stuffed in your pocket are requisitions for X-rays or lab tests, perhaps a suggested physiotherapy regimen and maybe a prescription for one or more medications. Ideally you've discussed the planned medication with your doctor — what it is, what it's for, how and when to take it. But often the doctor is rushed, or you forget to ask, or because you're worried or surprised you don't remember exactly what the doctor said.

You now have a number of choices. You can get the prescription filled, follow the directions and hope for the best. Or, you can telephone your doctor and get things clear on the phone. Or, you can turn to an excellent source of information: the pharmacist. Before filling your prescription, even if you think you have all the information, ask to speak with the pharmacist. She or he will be pleased to help you sort out medications and to read your prescription with you. That's part of their job.

You may choose to have the original prescription filled near your doctor's office. Any repeats can be transferred to a convenient pharmacy of your choice. The original must stay where dispensed and the details of transfer vary between provinces. Both doctors and pharmacists are licensed by province, so your prescription must be dispensed in the province in which it was written.

The first thing you may be asked in the pharmacy is, "Would you please spell your name?" This is just a quick check to make sure you weren't given somebody else's prescription.

On your prescription the drug is described by strength, quantity and the way it is to be taken. The format is: drug by trade or chemical name with

strength and form (capsule, liquid, ointment), the quantity the doctor chooses for you (*mitte*) and the directions (*sig*). Latin abbreviations are still used and the quantity may be given in Roman numerals. So the same prescription to be taken for 60 days may be written *mitte:LX* or *mitte 60*. The metric system is commonly used to give weights, volume and strength. Also don't forget that either generic names or trade names may be used. The box on this page gives two examples of typical prescriptions and an explanation. The only difference is that this writing, unlike many doctors', is legible.

Before the pharmacist begins to fill your prescription, discuss any options you may have. Perhaps the antibiotic is needed right now but you can put the cough syrup on hold, or vice versa. You can discuss a tryout of a long-term prescription: start with a two-week

supply to see that the drug will not upset you. After the trial, order the larger quantity and take advantage of the better price. This trial basis is important if you have had previous reactions to other drugs.

The following questions are simple and will help you take your medication safely and get your money's worth.

Do I need a prescription for this?

Doctors are often in the habit of writing all their suggestions as a prescription (Rx) even for over-the-counter drugs (OTC). Many third party insurance plans such as Blue Cross, Green Shield or provincial government benefits will pay for prescribed over-the-counter drugs. If you have an insurance plan you will need a proper receipt to make a claim. But if you don't have drug insurance, it is cheaper to buy OTCs without the prescription.

Is there a generic equivalent for this drug? You may have a choice and often the generic drug is substantially cheaper. This is because of the way drugs are developed and marketed. First, a company identifying a potential market researches and develops a new drug — often a lengthy and expensive process. Then they vigorously market it under their trade name, buying glossy advertisements in medical journals and giving out drug sam-

Reading a Prescription

Rx

- Cimetidine 400 mg
mitte: 60
sig: i tab po bid pc

Cimetidine in 400 milligram tablets
60 tablets
i tab = 1 tablet
po (per os) = by mouth
bid (bis in die) = twice a day
pc (post cibum) = after meals

This appears on your label as: Take one tablet by mouth twice daily after meals.

- Erythromycin 125 mg susp

sig: po tid x 10 ds

125 milligrams of Erythromycin suspension which is contained in 5 millilitres of liquid. Each ml has 25 mg of Erythromycin. (5 ml = 1 tsp.)
po = by mouth
tid (ter in die) = three times daily
10 ds = 10 days

This appears as: Give one teaspoonful by mouth three times daily for ten days.



Sylvia Macuinias

les and gimmicks to doctors and medical students. This is often the only education doctors receive about new drugs. The goal of a drug company is to make a profit and to get their drug well established before other drug companies acquire their formula and begin to release the same drug under a different name.

Because generic drug companies distribute drugs previously manufactured by a brand name company, they avoid expensive research and promotional costs and can sell their drugs more cheaply to the consumer. Standards of quality are supervised provincially so the consumer is assured of equivalence in strength and purity.

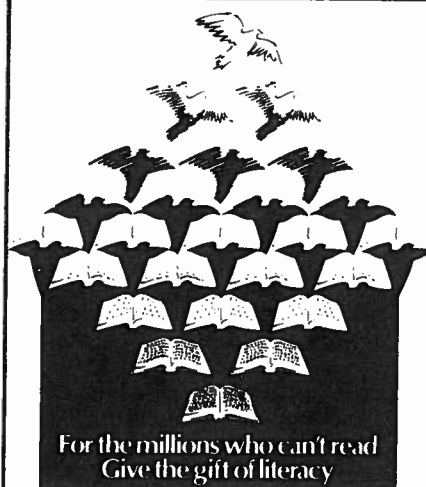
Can I take this with other medication? Your doctor should keep tabs on any other prescription medications that may interfere, but many people see more than one doctor for different problems. You and your pharmacist may be the only ones who know everything you're taking. Also check with the pharmacist about OTC products and drug interactions.

For example, the pharmacist might suggest that you keep up acetaminophen for fever and use other symptomatic relief like decongestants to make a child taking amoxicillin comfortable. Analgesics with codeine will

cause some drowsiness so don't add alcohol, antihistamines or tranquilizers. The combined effect is central nervous system depression; you could become a dangerous driver or have trouble concentrating. Drugs to treat high blood pressure and other heart conditions should not be taken with most decongestants. Many decongestants cause increased stimulation and irritation to the heart muscle.

Although you don't need extensive pharmacological knowledge, a basic understanding of how a drug works, what kinds of effects to expect and how to take it can only help you. Informed consumers tend to take medication properly and with more convictions, which can only lead to better results. Also if you are like many people who avoid taking medication whenever possible, knowing as much as you can allows you to make an informed decision about whether or not to take a prescribed drug. This basic knowledge is just one more part of assuming greater responsibility for your health.

Priscilla Cook is a practicing pharmacist. Trained in Saskatchewan, with an emphasis on counselling, she now lives in Toronto.



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ies and Services Branch. This study, conducted in 1986, documented an incidence of RSIs at Emerson. Using insurance and compensation claims alone, it reported 24 cases in all. Most of the injuries occurred in the winding department where Sheila and Linda work. Almost one in five winding department workers were suffering from RSI. While cases were reported in other departments, the rate of injury in winding was significantly higher.

Tendonitis and carpal tunnel syndrome were the most common conditions reported. Carpal tunnel syndrome is recognized by numbing, sweating, tingling and pain in the affected hand. The carpal tunnel is a structure inside the wrist formed by three wrist bones and a ligament. The tendons that move the fingers (carpals) pass through this tunnel of bones and ligaments. When the fingers and wrists are moved in awkward positions or at fast speeds for long periods, the finger tendons swell from rubbing against the wrist bones. Eventually the swollen tendons pinch the nerves in the wrist and reduce the feelings and mobility of the hand.

Twenty-three out of 24 cases at Emerson involved women. Statistics like these are common, and may be used by managers, or by some doctors, to suggest that women are more susceptible to RSI than men because of such factors as hormonal imbalances or small wrist size. But there is no conclusive evidence to support this view. More likely, more women complain of it because women do a greater amount of repetitive work. Fortunately for Sheila and Linda, their doctors recognized the cause of their disorders. Sheila said her doctor took one look at her and said "Emerson, right?"

There are treatments to relieve the symptoms of RSIs but there are no cures. Complete rest of the joint or limb affected, chiropractic adjustments, massage, ultrasound treatments, vitamin therapy and pain killers can all be used to relieve the swelling and pain caused by RSI. But the treatments cannot reverse the damage done, nor keep the pain and swelling from returning. Often workers with these injuries are forced to quit their jobs.

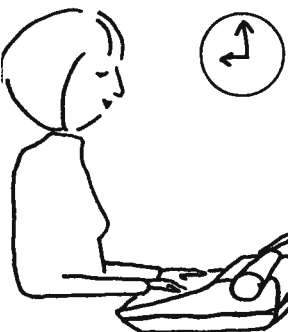
Sheila has tried the treatments, and while they got her back to work for awhile, they did not heal her: "I went to a physiotherapist for ultrasound and massages, I rested my arm totally for three months, and I took pain killers. Now, I'm back at work again but it still hurts."

Linda, at 24 years of age, has been advised to quit her job: "My doctor says he could keep me off work for a year but the tendonitis would come back as soon as I went back to repetitive work. He says I should quit my job before my health gets really bad."

For a worker temporarily disabled with a Repetitive Strain Injury, compensation is fairly easy to get from the Workers' Compensation Board (WCB) if she/he has a doctor who will support her/his claim that the problem is work related. For workers permanently disabled, compensation is a totally different matter. The WCB will assist the worker with job retraining, it may supplement the worker's pay in a lower paying job, but it will *not* keep paying a worker unless it considers the worker totally disabled. And while workers like Linda are disabled from the work they are trained for, in the eyes of the WCB they are *not* totally disabled.

Linda hopes to find other work but it will be difficult to find a job that does not involve repetitive work and which pays well, particularly in a town the size of Napanee. Linda's doctor told her she could go back to Emerson if there was "modified or light work." By modified work, he meant any work that would not aggravate her condition. When she asked the plant manager about modified work, he told her, "There's no such thing at Emerson."

Rather than trying to accommodate Linda, as an employee injured by her work with the company, Emerson has actually tried to fire her. "The company told me I was fired because I didn't bring a doctor's note in soon enough. We're supposed to bring a doctor's note to work within three days when we're sick." This company rule is supposed to ensure that workers do not take time off without legitimate health reasons. In Linda's case, it is hard to imagine that a note was necessary to prove the legitimacy of her absence. She had just returned to work from time off on compensation, and



she had phoned in to explain her absence.

As a union steward, Sheila got after the company for its treatment of Linda. "I told them they had no right to fire her. She phoned in. She hadn't even received their registered letter requesting a doctor's note when they told her she was fired." When Linda took her doctor's note in, one of the managers told her it was not good enough. In frustration, she told him it did not matter because she had to quit her job because of her health anyway. Linda was under the impression that she would have to formally quit her job in order to qualify for alternate work supplements or retraining from the WCB. But that is not the case.

In fact, it is very important that Linda not quit because she would then lose her recall rights — her rights to return to a job in the plant. But she must inform Emerson that she is available for modified work. If WCB finds her other work, Emerson will lay her off, not fire her, and she can return to the plant if she gets better, or if modified work does become available in the future. Workers at Emerson used to lose their recall rights as soon as they were out of the plant for more than a year, no matter what the reason. As Sheila explained, "Under the new collective agreement, workers can be out on compensation for up to two years before they are fired, and even then, it's not automatic any more."

Some people in the plant were applying for disability insurance offered by the company, instead of applying for compensation from the WCB. This strategy hurts workers individually and collectively. Individually, it hurts workers because they get less money, for less time, with no guarantees of coverage for future problems. Unfortunately, as Sheila explains, people file under insurance plans because they get paid faster.

"You don't get paid for the first five days you're off, and you only get paid for up to 16 weeks, but you do get paid right away. With compensation, you have to wait for 5 or 6 weeks before you get any money. Sometimes people just can't afford to wait that long. But on compensation, you get paid from day one, and you get paid more

money, 90 per cent rather than 60 per cent of your earnings, and you're covered for a longer time if necessary." In addition, when workers go off work on insurance plans, their health problems are not recorded as work-related. Should their problems get worse in the future, these workers will find it very difficult to get assistance from the WCB because they will have no records documenting their problems as work-related ones.

Collectively, this strategy hurts workers because it takes the pressure off the company to improve working conditions. Employers' payments to WCB are based on the number of claims filed for their workplaces. This payment system is supposed to provide a financial disincentive to those employers who do not protect their employees. When workers file their claims under insurance plans, instead of with the WCB, that financial disincentive is removed.

Often people continue working with incredible pain because they feel there is only one option — quitting. But RSI can be prevented. Work stations, tools and equipment can be redesigned to prevent awkward positions and reduce twisting actions. Single-task jobs can be eliminated. The pace of work can be reduced. And if all else fails, workers can rotate between jobs that require the use of different muscles.

It is usually the workers who have an intimate knowledge of their jobs, who know the kinds of changes required to improve them. "There are all kinds of little things the company could do that would cost them next to nothing," Sheila says. "For instance, there was piping along the side of the assembly line that made the job awkward. It forced us to lift the motor off the line, when it would have been easier to slide it off the line. I asked the supervisor to have it removed."

Sheila also proposed job rotation for her line because everyone on the line was doing similar work and suffering from similar problems. "I proposed rotation for the line. We were all handling the same motors but doing the same action over and over again. I asked the other people on the line if

they wanted to rotate — they did. That way we're using different muscles." In Sheila's situation, job rotation helped because it allowed workers to vary their actions and to use different muscles over the course of a work shift. But job rotation is not a perfect solution. In many instances, it will not help at all because different muscles and movements are not involved. In other instances, it will be harmful because it actually increases the number of people exposed to the injurious jobs.

The Ontario Ministry of Labour has offered a series of concrete recommendations for reducing RSIs at Emerson. For instance, they suggested that adjustable standing platforms be provided to the workers in the winding department so workers could adjust their heights to their working surfaces. Linda feels that standing platforms would really help. "As it is, you're working with your arms up all day so your shoulders get tense and sore. When I was working on 'simo-insertion,' a job in winding, they gave me a standing platform for a few days. It made the job a heck of a lot easier."

Unfortunately, the ministry did not back its recommendations with the authority of an order. The union pressed the enforcement branch to use the general duty clause [Section 14(2)(g)] of the Occupational Health and Safety Act to order the company to implement the study's recommendations. Despite the staggering injury rate documented in its report, the ministry chose only to *advise* management to adopt the study's recommendations.

That was August, 1986. Since that time, the company has started to examine the design of the workplace but its ergonomic committee is composed totally of management members. They have failed to include any union members on the committee. And as the union expected, little has changed in the plant. "They brought in one chair for us to try in winding. It's totally adjustable — the seat goes up and down and the back moves in and out. I used it once — it's good — my back was not so sore at the end of the shift," Sheila explains. "But who knows how long it will take them to get chairs for all of us?"

When it became clear that the ministry was not going to order the com-

pany to make the changes necessary to prevent further injuries in the plant, the union called a general meeting. We summarized the findings and recommendations contained in the ministry's report, and then we encouraged people to exercise their rights to refuse unsafe work. This right to refuse is enshrined in section 23(3) of the Occupational Health and Safety Act. A worker has the right to refuse work where he/she has reason to believe it will endanger him/herself or a co-worker. As far as the union is concerned, work that produces RSI endangers a worker's health, and workers have the right to refuse it.

“People are scared to refuse to do something that is part of their job . . .”

In what has become a precedent-setting case, Linda refused to do repetitive work that she believed would harm her health. “I had told the company that I did not want to do the ‘dip and bake’ or ‘tuck and block’ jobs because they were hard on my shoulders. I gave them a doctor’s note saying that I shouldn’t. So on August when they asked me to do the ‘dip and bake’ job, I refused. I gave the foreman a union leaflet outlining the steps of a refusal so he knew what I meant. He told me there was no other work to do. There was all kinds of other work that I could have done . . . but they sent me home without pay.”

By law, there are a series of steps that must be followed in a work refusal. Most importantly, the union health and safety representative must be called, and if the problem cannot be resolved, a ministry inspector must be called in. The refusing worker is not to be penalized in any way for exercising his right. The union believes proper procedures were not followed by the company in Linda’s refusal, and she was penalized.

The ministry became involved only when the union health and safety representative called to complain about the improper procedures. The ministry, while recognizing Linda’s

refusal as genuine (she did have a reason to believe that it could harm her) did not uphold her refusal because the job was “unlikely to cause injury to a normal healthy worker.” In other words, the ministry will not uphold a work refusal when the work is hazardous to the worker for a reason particular to that worker. This interpretation has wide-ranging implications. For example, a woman could not refuse to do work that would be dangerous to her pregnancy. In the Emerson case the ministry did advise management that “it would be prudent” in the future to treat similar situations as refusals and to follow the procedures outlined in section 23 of the act.

Not only did the ministry fail to uphold Linda’s refusal, it failed to charge the company for violating the Occupational Health and Safety Act. The union, concerned about the precedent of such a decision, and about its impact in the plant, responded in four ways:

The union wrote to the regional manager of the Ministry’s enforcement branch demanding to know what actions would be taken against the company for its violation of the act. The union also wrote to the company demanding that it pay Linda for the shift in which she was sent home. Third, the director of the enforcement branch was notified of our desire to appeal the inspector’s decision on her refusal. Finally, union members handed out leaflets in the plant to let workers know that we were not going to accept the shoddy treatment of Linda’s refusal.

Five months later, the issue is still unsettled, but morale in the plant is good because workers feel they can fight back. Sheila says that there have been a lot more refusals in the plant since people became aware of their rights to refuse. “I’ve gotten to the point where I call my foreman every time a stator gets stuck — I let him take it off. Other people are starting to do the same thing — refusing to pound stators with their hands when they get stuck.” Sheila says that people have to know that they will be supported if they exercise their rights to refuse work. “People are scared to refuse to do something that is part of their job, but if there’s someone around who will back them up, they will. People in my area know now, that as the union stew-

ard in the area, I will back them, so they’re refusing more often.”

There is no doubt that a work refusal is the most effective way to get action on health and safety problems in the plant. It is important to raise concerns in the joint health and safety committee meetings, but that has proven a poor vehicle for change. It is too easy for employers to drag their feet on committee recommendations.

We cannot rely on the ministry to provide safe workplaces. Time and time again, it has demonstrated an unwillingness to interfere with the “internal responsibility system” — a system that leaves enforcement to the joint health and safety committee in the workplace. The ministry chooses to play the mediator, rather than the enforcer, whenever it can.

Work refusals force employers to recognize and deal with health and safety concerns. And failing that, they force the ministry to fulfill its role as enforcer, not mediator, of health and safety legislation. While work refusals are currently a worker’s most powerful right, the onus is on the individual to exercise it. The labour movement has been pushing for the collective right to refuse in order to take the pressure off the individual. The union rep should be able to shut down an unsafe operation on behalf of all workers.

Sheila says that things are changing in the plant but it is only because the union representatives keep pushing on health and safety issues, and because workers in the shop are catching on to their rights. “The company is down 100 per cent on our health and safety representative because he keeps pushing them. The company is starting to do things but only because we got their backs against the wall.”

Repetitive Strain Injury is not isolated to Emerson. It is pervasive throughout all sectors of industry. As the trend toward automation increases, repetitive work will become harder to avoid. It is time for repetitive work to be treated as the serious occupational health hazard it is, by employers and government alike.

Kim Perrotta is a research officer at United Electrical, Radio & Machine Workers of Canada.

MY STORY, OUR STORY

Celia's Blessingway

Judi Pustil

For years I thought about giving you, my daughter, a blessingway when your first menstruation came. We had spoken of it often, you and I, ever since I first learned about blessingways from New Mexican midwives years ago. Traditionally the Navajo Indian women honoured the maidens of their communities who were walking into womanhood with these sacred rituals. And, I have always known that I would some day honour you, Celia, in a similar way. Since then, I have honoured this awesome right of passage with many of the women with whom I have been graced to share pregnancy, birth and motherhood.

I remember a few weeks before your 13th birthday, feeling a strong impulse to make plans for your blessingway with you. I could feel in my bones, way deep in my centre, that your first period was not far off. Perhaps I was remembering, though not consciously, that I was your age when I first got mine 23 years ago. We went for a walk together, you looked at me and said, "Well maybe I shouldn't have a blessingway." I felt sad and disappointed, but I listened as you explained the difficulties of living in two quite different worlds; one the world you share with me and Micah in which you are surrounded by my friends and the values and culture that we honour. That world, though there are many parts to it, has supported and prepared you to celebrate your first blood in a ritual with your tribe of women around you. Friends and elders alike. The other world you share with your friends, at school and in the day to day world. For the most part that world does not support or prepare you for such a passage.

I could feel what a conflict this was for you. I knew that you wanted to be able to share your blessingway with your friends, but you knew in your heart that they would not really under-

stand or feel comfortable there. And then I watched you accept the deeper truth inside of you. You really did want to share it with the women you were close to. It was a truly beautiful moment, and once again it taught me to trust you and have faith in you. Which I do.

As we talked and planned I told you I wanted part of it to be a surprise. You wanted only women there, outside, near the mountains, water and sky. You asked that every woman bring a blessing and something sacred and symbolic of womanhood to put into your medicine bag. We would dance and sing and feast. And the women who had daughters would bring them, because you felt it would be important for those daughters to witness and share in this ceremony and in some way begin to prepare for their own time to come.

About a week or so later your period came. I began to feel from you that getting our first period truly is a profound passage, a door opening, a spiritual transformation that deserves our utmost attention and indeed honouring. Here you were moving with the power in you and finding your own way.

In the next couple of weeks until the blessingway, many things percolated in my being. I felt like it was a rite of passage for me too. It was in my consciousness all the time. I spent a lot of time planning for your blessingway with our friends. Every woman's hand and heart was part of the creation. We wanted to do all you had asked and we knew that something very important needed to happen there too, some kind of test or challenge — a vision quest, that was appropriate for this occasion.

Traditionally, women did send the maiden on a quest in solitude to face her fears and come to know herself in a new way. She would meditate on her

totem, power animal, or symbol, so that she could bring back something about herself, her true nature, and her own power, to hold with her always. The women of the tribe would support her in song and spirit while she was gone, and would welcome her into their circle as a woman among them on her return. We wanted to do something with you that would symbolize all of this, that would be meaningful and true to you and to us.

Your blessingway was five days before your 13th birthday. Every cell of my being was excited and opened wide that whole day. I could feel the power of the occasion pulsing through me. I could feel your excitement and anticipation too. In the morning I made the festive challahs that were going to be my contribution to the feast afterwards. I poured all of my love and reverence for you into those breads.

We had called it for four in the afternoon, and you and I decided to go early to set up and spend a little time alone, before everyone else arrived. After we got organized, you asked if we could lay on the sand together for a bit and hold hands and be quiet. So we did. I will never forget how beautiful and peaceful it was there with you just then. It was very precious and timeless. The ritual had begun. At four we all gathered beside the mountains and under the sky to celebrate your womanhood, 11 women, four daughters aged two weeks, five, seven and 12 years old, and you.

We began making music together on the beach, and started the fire going. Then we cast a sacred circle around us invoking the spirits and energies of the four elements and the four directions. We called on the presence of our elders, the ancients, especially Bubby Celia whom you were named after. We asked for the power of the Goddess and all of the great spirits to guide us that day. We did a cleansing together with the aromatic smoke of sage, one of the herbs used by Native people to purify, and stood around the fire and gorgeous altar we had created with the flowers. Everyone looked so wonderful that day, especially you. Then Nan told us all a story — of the way it used to be in the old days when women came to their first blood and the sisters and mothers and grandmothers and aunts and friends gath-

ered to honour them and to celebrate. She told us about a joyous time when women were free and their power could be expressed freely and openly without fear. She then told about the changes that came, that made it impossible for women to share openly, how their power was taken away, and what sad times those were for women. She told about the future too, how the time would come again when women would be free to celebrate in a similar way, gathered as we were on the beach in nature's arms, with our sisters, with our tribe of women surrounding you to honour you.

After that everyone formed two circles around the fire; an inner circle of children, which you would join, and an outer one of women. You were going to leave the circle of children and go off by yourself on your quest and not return until you could let us know that you had found it. It didn't matter how — through something you found, saw or experienced, or brought back. You took the unicorn you had agonized over the night before as the symbol of childhood you would leave behind. The other girls accompanied you down the beach a ways and then left you to go on alone.

As you started off, I told you that our love and support would be with you to help you on your way. We would sing and chant power songs for you until you returned to us. I will never lose that vision of you walking along the beach.

While we sang for you, the women dressed me as the spirit of womanhood. I put on a long beautiful embroidered dress, with a black shawl symbolic of death, a white cord symbolic of birth, and a red scarf over my womb symbolic of fertility. Maureen made me a beautiful flower crown to wear. I wore my healing pouch, and another woman found me a branch to hold, symbolizing regeneration and growth. We sang and then we saw you returning.

Maureen and Ilene brought you to me as you neared the circle of women. I faced you and asked who you were. Celia, how beautiful and pure you were as you simply and strongly answered me. You were so soulful as you told me you had found the power and spirit, the essence of your womanhood. You held up a piece of driftwood and a pearly everlasting flower. As you



Terri Robertson

stood out there on the point alone, you realized it was time to let go of your childhood, so you threw your unicorn into the lake and let out a scream. Then as you turned around right there in front of you were the driftwood and the flower so you picked them up and looked at them for a while.

I will never be able to do justice to what you shared with us just then, or the beauty of that moment and how deeply it struck all of us. It truly was like seeing your pure essence, pure and clear and deep. You said the driftwood was stuck between two rocks and you had to gently pry it out. It reminded you of that part of yourself that had been stuck as a child and was now ready to come out. The pearly everlasting you said you picked because to you it is like a woman's soul — you can pick it, but it will never die. We were all quite awestruck. I felt so moved. I embraced you and adorned you with all the symbols I had been wearing as the 'gift of womanhood'. You were shining and so beautifully proud.

We each embraced you and gave you our gifts and blessings. We sang to you as we welcomed you and received



Terri Robertson

you and accepted you into the circle of women. I said that though you had clearly left your childhood behind, I hoped you would never lose touch with that beautiful, innocent and pure child inside you, that you would always listen to her, nurture and care for her, and let her shine through. She would be a very essential part of who you truly are as a woman now.

We feasted on all the delicacies we had brought in your honour. And what a feast. As darkness slowly came, you asked us to sit around the fire together and tell stories of our first blood. I could see that for you it was an essential part of the whole ritual, a way to gather your heritage and weave the stories of your woman tribe around you. It was truly amazing for all of us to share those stories with you and with each other.

Your blessingway was a real healing Celia, a deep healing for all of us. That night was the saddest and the happiest experience of my life. The saddest because it didn't happen for me when I was your age. How special and wonderful it would have been. How much I needed it. How much we all need it and deserve it. It is our birthright. It was the happiest because of how right and perfect it felt to give that to you. In fact the next best thing to having it myself was to create the love, support, and honouring for you, my daughter. It fed me too. It healed so much of that place in me, even after all these years. It is never too late. I think we all shared that feeling to some degree.

The whole experience moved me and still affects me on many different levels. It runs deep like the ocean.

As we packed up our things and headed up the road back to the cars, a gentle rain started to fall. Perfect timing. In our hearts we all knew that we had begun something very sacred and very important among us. A new tradition in our community of women. Bless you my daughter for being a pioneer woman and showing us the way.

Judi Pustil lives in Nelson, B.C. with her children Celia, 13 and Micah, 10. She is a midwife (though not actively practicing at present), and childbirth educator. She is currently spending a lot of time with her children and doing bodywork, counselling, and writing.

Mary J. Breen
Janis Wood Catano

Can She Read It?

Readability and Literacy in Health Education

You can read. Most likely, you can read very well. Like most of *Healthsharing's* readers, you probably have a post-secondary level education. *Healthsharing*, and a large proportion of all information on women's health, is written for skilled readers like you. Sadly, according to Statistics Canada, this excludes at least two million women in Canada.

As women and as feminists we have invested our energy in recognizing, understanding and celebrating all the things women share — our bodies, our strengths, our dreams. In focusing on what women have in common, we have overlooked some important differences. One difference is that even when we share common languages, we don't share common reading ability. The Statistics Canada estimates of two million women with reading problems may be very low. Anyone achieving grade eight at school is assumed to be able to read, and no one yet has established good estimates of the numbers of immigrants who can't read one of Canada's official languages.

Of these two million women with reading problems, five hundred thousand can't read at all. The remaining one and a half million are functionally illiterate. This means that although they have some reading skills, they find reading and understanding printed materials so difficult that they are often unable to use community programs and services such as legal aid clinics, which require the ability to fill out complicated forms. They may not be able to read the directions on over-the-counter medication labels.



L. Emily Elliott

They can't read a consent form in a hospital and they can't read or benefit from *Healthsharing* or from most of the material produced by the women's health movement.

To us as skilled readers, it sometimes appears that the world is glutted with information about health and health care issues. In addition to the wealth of information produced by the women's health movement, magazines, newspapers, consumer publications, public health brochures and books confront us at every turn. From this information, we better understand the power that the medical system has over women's lives. We have learned about things like safe childbirth and birth control, about dangerous drugs and safer alternatives. We have learned to see menstruation and menopause as normal, healthy processes rather than as illnesses. We have learned to organize in opposition to the existing system and to create alternatives which

respect and respond to the real needs of women.

In short, this information has become a vital and empowering fact of our lives. But for the one and a half million Canadian women who have limited reading skills (not to mention the half million who cannot read at all) this information might as well not exist.

What's the problem?

Writing involves two parties: the writer, who transmits information and the reader, who receives it. The more the writer understands about the reader, the more effectively she can transmit the message. Adult educator J. Roby Kidd put it this way: "The first task of the teacher is to learn from the students the concepts that concern them and the images and language they best understand." The North American women's health movement was initiated largely by well-educated, middle class, white, able-bodied feminist activists who wrote for other well-educated, feminist activists. The literature they have produced accurately reflects "the concepts that concern them and the images and language they best understand." This is the problem. Although this material is invaluable to the women who wrote it and to women like them, these feminists represent only a small proportion of women. What is there for everyone else?

Recently, as women's health has become a more respectable and profitable topic, literature has appeared which addresses the same health issues initially addressed in feminist

MENOPAUSE

Prevailing Social Views

Stereotypical thinking about menopausal women includes many myths (many created and perpetuated by doctors and psychiatrists).

The first thing that comes to my mind about menopause is FALLACIES: menopause is blamed for every mood change and unexplained feeling, the way menstruation is with younger women; also discrimination and derision—"she must be going through the change."

Helene Deutsch, a disciple of Freud, referred to menopause as women's "partial death." Mastering psychological reaction to menopause was, she said, "one of the most difficult tasks of a woman's life."¹³ It would be more accurate to say that our most difficult task is mastering reaction to the cultural stereotype of menopausal women, a process which is complicated and made even more difficult by the fact that we cannot help internalizing that image to some degree.

The "raging hormones" myth describes menopausal women as so incapacitated by hormone fluctuations that they are incapable of rational thought and behavior, and should certainly not hold any kind of responsible position.* A more recent myth, part of the "superwoman" mystique, suggests that the usefully busy woman will hardly notice menopause at all. Neither extreme is accurate or helpful to women.

MENOPAUSE or "The Change of Life"

People have a lot of wrong ideas about menopause. Many people think that it is a time when women go a little crazy, that they get terribly depressed and fat, and that they lose all interest in sex. This is simply NOT TRUE. Most women do not have a very difficult time. Menopause is a natural stage which we all go through. It is not a medical problem or a disease. If we know what to expect, and if we get lots of support, we can go through it without too much trouble.

Excerpts on menopause from *The New Our Bodies, Ourselves and Taking Care*.

literature, but which avoids the political implications inherent in a feminist analysis, packaging the material in a more popular format. Despite the fact that as feminists, we may deplore the apolitical stance of this material, much of it is written at a somewhat lower reading level. Because of this, it has provided information to thousands of women the women's health movement has not reached. But even this material assumes a level of reading skill beyond that of 20 per cent of the Canadian adult population. Doak, Doak and Root, in their book *Teaching Patients With Low Literacy Skills*, illustrate this point by citing a study in which only 32 per cent of 291 commonly used health education materials were readable by the majority of Americans.

Easy-to-read resources

Both of us have been involved in the development of an easy-to-read health resource. Mary has written *Taking Care: A Handbook About Women's*

Health (supported by the Health Promotion Directorate, Ontario Region) and Jan has written *Nobody's Perfect*, a resource for parents of children from birth to age five (produced by the Health Promotion Directorate, Atlantic Region). We are not suggesting that our works are model easy-to-read materials. We offer them as examples to show that the process of producing such materials is within any writer's capability. While these works are not perfect, we know from reader responses that they begin to fill an otherwise unmet need.

To illustrate the assumptions inherent in the writing and organization of most health information, and to show that this kind of information can be tailored to meet the needs of an audience of readers with more limited skills, we have compared our resources with material on the same topics written for more highly skilled readers.

We chose the feminist classic, *The*

New Our Bodies, Our Selves, by the Boston Women's Health Book Collective, and Penelope Leach's more middle-of-the-road, *Your Baby and Child From Birth to Age Five*. Both are popular, widely available resources which contain an enormous amount of information of great interest and value to many women. However, because of the reading levels, assumptions about background knowledge, organization of information and even the type size of these books, the information they contain is available only to skilled readers.

The first example compares sections on menopause from *The New Our Bodies, Our Selves and Taking Care* (Example 1). The intent of both sections is to give a brief overview of commonly held misconceptions about menopause before going into detail about the experience.

It is apparent, on reading the excerpt from *The New Our Bodies, Our Selves*, that it is written for well-edu-

cated women with feminist leanings. In order to understand these three short paragraphs, the reader must have a variety of skills:

She must be able to read and understand words like stereotypical, menopausal, psychiatrist, psychological, myths, fluctuation, fallacies, discrimination, mystique, incapacitated, and internalizing.

She must be able to understand sentences containing as many as 45 words, including six verbs and several embedded clauses.

She must understand commonly held ideas about the raging hormones myth, which refers to a traditional view of women as hysterical and imperfect.

She must be familiar with the importance that the women's health movement ascribes to the way in which Freud's theories have shaped how women are viewed today.

She must know enough physiology to understand hormone fluctuations, enough sociology to understand the super woman mystique, and enough psychology to understand stereotypical thinking.

She must know how to interpret two different kinds of footnotes, one of which has a footnote itself. She must also know about quotation marks. She must be able to understand that in this book, italicized sections (without quotation marks) are quotes (from anonymous women), and that they may sometimes contain other quotes (with quotation marks) from other speakers. In a later sentence, she must also understand that some words within quotation marks refer to the words of other speakers, and others refer instead to popularly used phrases.

She must be able to read written material assessed at a grade 16 level.

Menopause or "The Change of Life," from *Taking Care*, tests at a grade eight reading level and assumes only that most women will have heard something negative about menopause at some point in their lives.

The second example compares the process involved in locating information on a specific topic in *Your Baby and Child From Birth to Age Five* and *Nobody's Perfect*. For our comparison we chose nightmares, a topic of considerable interest to the parents of many preschoolers.

F

FEAR of anger 115, 261, 273, 280, 318-319, 324-325, 326, 327, 421; of the bath 84, 227-228, 312; of blood 391; of the dentist 389; of falls 82, 189, 239, 245, 247, 329; and general anxiety 275, 302, 318-323, 327, 377, 392; lack of in accident-prone children 410-411; of toilets 309, 381; in the night 221, 301-302, 377-379, 386; and phobias 321-322; of separation from you 158-159, 194, 198-200, 215, 216, 220, 221, 223, 299-300, 318-319, 330, 332-333, 390, 396, 397, 398; of specific objects 189, 232, 298, 313, 320-321; and startling in the newborn 83, 96, 97, 103, 105-106; more response 109, 113, 114, 180, 232; of strangers 200, 232-233, 263, 319; of the unexpected 232-233, 335; and worries in pre-school children 391-392, 407-408, 421

SLEEPING AND WAKING first days 90-94; first six months 146-148; six months to one year 215-223; one year to two and a half 295-304; two and a half to five 375-380; bags 148, 221, 246, 301, 303, 304; and cold and warmth 80-81, 92, 98, 148, 158, 220-221; and colic 148; difficulty in settling

for 203-204, 215-220, 298, 299-300, 317, 319, 375; disturbances to 82-83, 92, 97, 98, 105, 220-222, 300-304; and feeding 51, 73, 94, 125, 133, 140, 142, 146, 148, 194-195, 204, 215; early separation from wakefulness 90, 92, 146, 148; hours 82, 94, 106, 134, 146, 158, 193, 215, 295; keeping himself from 215, 298; and naps 107, 146, 148, 193, 215, 223, 295-296, 423; waking from 296; "nasty thoughts" 377; and night-lights 92, 216, 301, 319, 321, 380, 384; and nightmares 301-302, 319, 378; and night terrors 378-379; and night wandering 302-304, 377; and overtiredness 99, 104, 215, 296, 298, 301; patterns of 32, 72, 73, 134-135, 142, 146, 148, 214, 221, 223, 295-296; places to sleep 90, 92, 93, 94, 148, 216, 303-304, 375-377; sharing 223, 375, 380; positions for 74, 93, 158; resting without 243, 298; "sleepy" babies 51, 106, 133; soothing and 98-100, 157, 216-218, 319; talking during 379; wakeful babies 106-107, 147, 148, 158, 223; waking early in the morning 148, 223, 261, 304, 380; waking in the night 220-221, 300-301 *see* COMFORT HABITS;

SOLVING SOME COMMON BEHAVIOUR PROBLEMS 17

- Sometimes They Drive Me Crazy 17
- Bedtimes 18
- Bedwetting 20
- Biting 22
- Clinging 23
- Crying (Babies) 24
- Eating Problems 26
- Fears 27
- Fighting 28
- Jealousy (New Baby) 29
- Lying 30
- Nervous Habits 31
- Nightmares 32
- Saying "No!" 33
- Sex: Kids' Questions 34

Index entries on FEAR and SLEEPING, reproduced from *Your Baby and Child from Birth to Age Five*.

✓ The entry on Nightmares from *Behaviour*, one of the five booklets which make up *Nobody's Perfect*. The original is in full colour.

2 Nightmares

What's Happening Here?

My child wakes up screaming from nightmares.

Why Is It Happening?

No one knows for sure what causes nightmares. They seem to happen more when a child is upset from things like: new baby, illness, new babysitter, toilet training, moving, scary T.V. programs, family problems.

What Can I Do?

When your child wakes up frightened, go to him at once and comfort him. Tell him it's only a dream. Give your child a bit of extra praise and attention for a while.

What If It Doesn't Work?

If your child seems to be having more and more nightmares, or they seem very upsetting to him, talk the problem over with a doctor, public health nurse or mental health worker.



Your Baby and Child is a 512-page book. It has a very brief table of contents and an extensive, extremely detailed encyclopedia/index. To locate information on nightmares, one begins in the index, under N. The entry Nightmares tells you to see FEAR; SLEEPING. Turning to F, you locate FEAR only to discover that the entry is 23 lines long and contains 93 separate page references on 17 different kinds of fear. Nightmares is not listed, but fear in the night sounds close. Fear in the night refers you to pages 221, 301-302, 377-379, and 386. Your next step is to begin locating and reading the specified pages until you find the information you want. And you still haven't looked up the other index reference, SLEEPING. If you do, you discover that there is no separate listing for SLEEPING. SLEEPING AND WAKING seems close though, but is even longer than

the entry for FEAR. Finally, a bit more than half way down the entry, you find Nightmares 301-302, 319, 378. This has been a complicated search requiring sophisticated skills and considerable persistence.

The intended audience for both *Taking Care* and *Nobody's Perfect*, was clearly defined as people, primarily women, with low reading skills. For *Taking Care*, members of the intended audience were involved throughout the book's development. A survey was done to determine which topics they wanted included in the book; a group of women from the intended audience met regularly with the author to review and discuss drafts of all the material, and revisions were based on their input. For *Nobody's Perfect*, consultations with the intended audience were undertaken before research and writing began, and those topics and issues

identified by the audience as being important to them formed the basis for the content of the resource. After the initial version of *Nobody's Perfect* was completed, the intended readers were again consulted as part of a formal field test of the materials, and revisions and alterations were based on their reactions. These consultations not only identified prospective readers and allowed them to identify their own needs, the consultations also provided a constant reminder to everyone involved in both projects that they were working for *real* people with real needs. Defining the intended readers and learning their needs made it possible to develop resources that could meet those needs.

Our argument is not that *Our Bodies, Our Selves* and *Your Baby and Child* are wrong, and *Taking Care* and *Nobody's Perfect* are right. They are sim-

How to write for people with low literacy skills

To be readable by a particular audience, written materials have to be tailored to meet the needs of that audience. This may seem blatantly obvious, but it is often forgotten by writers of health information, who too often write what they need to say rather than what their audience needs to hear. The process of developing readable materials requires that the writer determine the needs of the audience and then produce materials which reflect those needs. This process is important in all writing; it is critical when writing for readers with limited skills.

The accuracy with which the writer is able to reflect readers' needs determines the readability of a particular piece of writing for a particular audience. Producing an accurate reflection is a two step process. First, the writer must develop a working knowledge of her audience: she must learn from them, both what they want to know and what they don't want to know. She must resist the temptation to write about what she wants them to learn. Only then can she proceed to the second step in which, based on her understanding of her audience, she produces materials which reflect their needs.

"Get to know your audience." As a first step in developing readable health information, this advice sounds simple. It isn't always. You need to meet the people you will be writing for, talk with them and keep talking with them. Don't start to write until you feel comfortable in your understanding of your audience. If you can't answer these questions about your readers you won't be able to reflect their needs.

- What is the sex, age, educational background, cultural background and economic status of your readers?
- What do they want to know about?
- How much do they already know (or not know) about it?

- How badly do they want or need to know this information? How highly motivated are they to acquire it?
- How well can they read? How much information will they be able to acquire from written material?

This process of getting to know your reader is crucial in developing effective written materials. Using an interactive model throughout the process of producing materials, is one of the most effective ways to ensure that written material is both readable and relevant to the intended audience. In an interactive model, members of the intended audience are involved and consulted throughout the writing process and their input guides the writer.

Once you've established contact with your audience and developed some understanding of their needs, you can move on to the second step: producing useable, readable materials. Writing for readers with limited skills is, in itself, a skill. For literate, highly skilled writers, acquiring this skill often involves unlearning many of the techniques which we have been taught are the hallmarks of good writing. We have to learn to consider:

The reading level of the material.

This is usually measured by a formula or other readability technique. A readability formula is a regression equation into which counts of language variables, like number of words per sentence, number of polysyllabic words, or number of sentences per 100 words, are inserted. The calculation from this equation yields a score which is interpreted as an index of the readability of the material. A word of warning: a readability formula is a useful tool when used to help guide the development of written material, but no formula is reliable or accurate enough to be used as a sole predictor of readability.

ply different: aimed at different people with different needs and abilities. Our intent has been to point out the degree to which information is overwhelmingly available to highly skilled readers, the reasons why this information is not accessible to readers with more limited skills and to offer some suggestions for remedying the situation.

Conclusion

To fully participate in our culture, you must be able to read. Illiteracy is not only an enormous hindrance, it is also an embarrassment. People will go to enormous lengths to hide the fact that they can't read, or that they can't read well. Because the problem is so well hidden, it's easy to forget that there is a problem at all.

Ideally, the solution is to provide whatever help is necessary to enable everyone to read well. In the short term we must make every effort to ensure that health materials are readable by the widest possible audience. Access to information alone will not enable individuals to deal effectively with the medical system. But information is a necessary step. It provides us with the tools to begin to understand, control and alter some of the medical system's power and influence over our lives. It connects women with other women concerned about these issues. The reader with limited skills, who is often poor and at much greater health risk, has very little access to this information. Unless more easy-to-read materials are produced, lack of information will continue to jeopardize the health of these women and their children.

Mary J. Breen has worked as an English as an Additional Language teacher. She was a founding member of the Vancouver Women's Health Collective. She is currently working on a revised version of Taking Care. Janis Wood Catano has a Master of Science degree in Health Education from Dalhousie University. She has taught for the Prepared Childbirth Association of Nova Scotia. She has written Teenage Pregnancy: A Resource Kit and Nobody's Perfect. Mary lives in Peterborough, Ontario and Jan lives in Halifax, Nova Scotia.

You can see a copy of Nobody's Perfect by contacting your regional Health



Dawna Gallagher

Promotion Directorate office. Copies of the revised version of Taking Care: A Handbook About Women's Health will be available starting October, 1987 from The Women's Health Project, 115 James St., Peterborough, Ont. K9H 1C7 (705) 742-9852. The only cost is postage.

Suggested Reading

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No. 6 But What will they Mean for Women? Feminist Concerns about the New Reproductive Technologies by Linda S. Williams.

Looks at in vitro fertilization, artificial insemination, surrogate motherhood, sex selection, and concludes that in the long run, reproductive technologies will further undermine what little control women have over their reproductive lives. \$2.50 + .75 postage, prepaid.

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REVIEWS

Labors of Love

Directed by Alvin Fiering, Polymorph Films, Boston, Mass., USA, Distributed in Canada by Canadian Learning Company (2229 Kingston Rd., Suite 203, Scarborough, Ont. M1N 1T8, 416-265-3334), 16mm and video formats, 33 minutes.

Reviewed by Jill Cameron

"I always knew that childbirth was a really magnificent thing, but until you go through it yourself, I don't think there's any way to describe it to anyone else; it's a really fabulous feeling."

a mother in *Labors of Love*

Labors of Love presents an intimate view of childbirth through a candid visual examination and first person narration of four couples' experiences. The 33 minute film is a useful introduction to childbirth and initial parental responses for couples expecting their first child, as it presents a general overview of labour in each of four different scenarios. However, the film gives very little technical information. There are few in-depth explanations and three of the four couples have uncomplicated births. The one exception is a birth by caesarean section, which had been anticipated by the parents. The scope of the film is therefore best suited to the uninitiated.

Labors of Love opens with the couples and their babies assembled in a living room, discussing their reactions to parenthood. "To hold Shawn in the delivery room... I think it was the most wonderful thing in my life. It was that clear, that simple to me. "I was so euphoric." The film has a generally upbeat tone that is encouraging to new parents, if perhaps unrealistic. The film does not show us if these individuals were hindered by postpartum depression, or if the transition from being a couple to being a family was really as smooth as implied

for all the couples profiled. From this general introductory discussion, the film moves to examine each case separately.

Lynn and Kerry's labour is slow and must be induced by pitocin, a drug that stimulates uterine contractions. Both the pump for the drug and the monitors placed on the mother's stomach are explained briefly by the administering nurse. Lynn compares the initial stages of labour to premenstrual cramps, a clear analogy for those who have never experienced this. She remains stoical and never loses control as the pain apparently increases. She seems to partially withdraw from what is going on around her, including a very eager, effusive husband. Kerry bounces from fluffing pillows to cranking up the bed, offering a constant stream of advice. Lynn finds that having to push and not being able to is the hardest part of her experience. The end result of Lynn's labour is a healthy baby boy.

Sherry and Charles have a caesarean birth, which their doctor had advised them early in the pregnancy might be necessary (although reason for a caesarean is not mentioned). An unusual feature of this delivery is that Sherry's mother accompanies her into the delivery room because Charles did not want to participate. The couple had discussed this and Sherry "felt his presence very strongly in mind and in spirit." The operation progresses smoothly and Sherry is very calm throughout the successful delivery of a baby girl.

Tory and David are the only couple with previous labour experience. With 13 months between her children, Tory expresses a common concern that she won't be able to cope with two very young children. Predictably, her fears prove to be groundless. This delivery features a midwife, in a hospital setting. This husband takes a relatively

passive role, helping when the midwife suggests, otherwise sitting beside his wife, offering emotional support. A very quick delivery results in the birth of a baby boy.

Theresa and Gary's birth experience is notable for the number of people involved and the general activity level. The couple walk, rock and talk throughout the process, with Gary massaging and holding Theresa most of the time. A midwife is also present in this birth, as well as a doctor, and a substantial background cast of friends. Although this baby boy initially needs oxygen, 10 seconds later he is fine and is otherwise healthy.

Labors of Love is an unimposing first glimpse of labour for first time expectant parents. Both the colour and sound are clear and the organizational form of the film is very effective. The director successfully moves full circle from the general discussion group of new parents to the specific case studies and back.

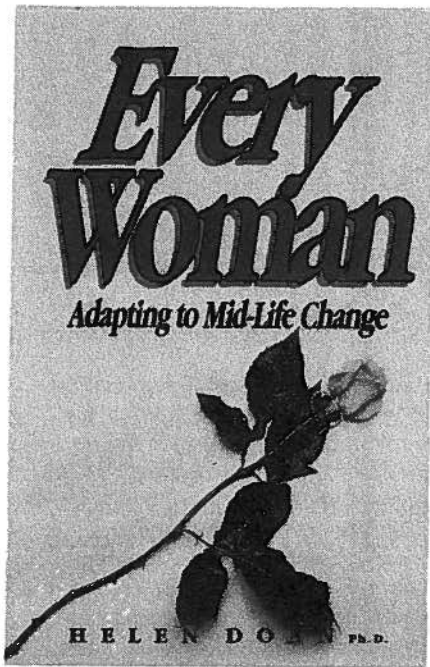
The quality of the information is less commendable. There are blatant omissions of very basic techniques such as an episiotomy or a forceps delivery. All of the women shown handle their deliveries with similar calm: where are the women who break down and request drugs or hurl verbal abuse at any animate or inanimate object in their range? Where are the problem births, the breech birth, the imperfect child, the premature baby?

We are not given the women's perspectives on the advantages and disadvantages of choosing even the options profiled: midwives, general practitioners, ob/gyns, caesarean. In the cases where the women were shaved, did they have a choice? Did the couple with a child want her to participate in the birth? The answers to these large and small questions would surely have made *Labors of Love* more appealing to a wider audience.

Despite this lamentable dearth of options and insightful probing beyond the surface, the film makes good use of its 33 minutes. It provides a worthwhile initial view of the complexities of labour for those who have yet to experience the "really fabulous feeling" of parenthood for themselves.

Jill Cameron is a freelance writer in Toronto and about to have her first child.

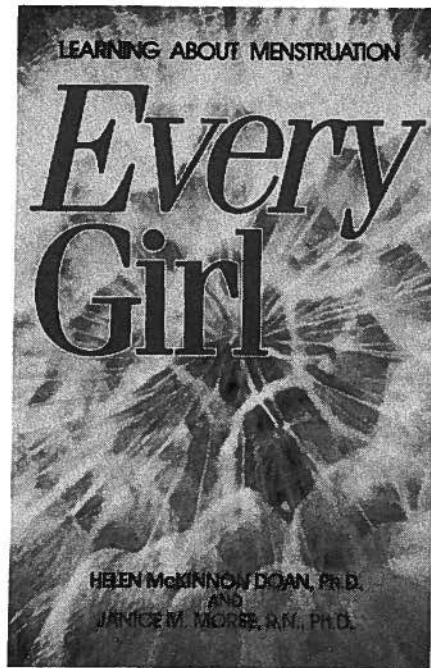
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RESOURCES & EVENTS

Women and Aids

A fact sheet, *Women and Aids*, has been produced by The Ontario Ministry of Health. Other available pamphlets cover such topics as *AIDS And The Workplace*, *Detecting AIDS*, *Information For Parents And Teachers* and *Information About AIDS*.

To order copies contact: Health Information Centre, 9th Floor, Hepburn Block, Queen's Park, Toronto, Ont. M7A 1S2.

B.C. Midwifery School

The B.C. School of Midwifery in conjunction with The Fraser Valley Childbirth Education Association needs support. The school functions without financial assistance from the government, and is supported by tuition, membership fees and donations. A yearly \$50.00 fee entitles members to their newsletter as well as discounts to seminars sponsored by the FVCEA.

Information and/or donations may be addressed to: The Fraser Valley Childbirth Education Association, 810 West Broadway, Suite 567, Vancouver, B.C.

Pap Tests

The Vancouver Women's Health Collective has produced an updated and expanded version of *A Feminist Approach to Pap Tests* by Robin Barnett and Rebecca Fox. This is an in-depth overview of pap tests, infections affecting pap test results and treatments of

cervical cancer.

Available from the Vancouver Women's Health Collective, 888 Burrard St., Vancouver, B.C. V6Z 1X9. Cost is \$3.50 including postage and handling.

Family Violence

The National Film Board, in conjunction with Health and Welfare Canada, has produced *The Family Violence Audio-visual Catalogue*. The catalogue has annotated listings for 16 mm films, videotapes, filmstrips and slide/audio-tape presentations. Topic areas addressed include child abuse and neglect, sexual abuse and spousal abuse. Resources available from approximately 100 different North American distributors are included.

Catalogues are available free-of-charge from the National Film Board. Photocopying of the catalogue is encouraged by the NFB.

Cancer Pain

A 25-page booklet entitled *Pain Relief: Information for People With Cancer and Their Families* is now available from The Palliative Care Foundation and chapter offices of the Canadian Cancer Society. The booklet, written in question and answer format, includes information about pain, use of medications and non-drug therapies, and family support.

The booklets are available free-of-charge. For more information contact The Palliative Care Foundation, 33 Prince Arthur Ave., Toronto, Ont. M5R 1B2 416-922-1281.

Non-Smokers' Rights

The Non-Smokers' Rights Association have produced an action manual for non-smokers entitled *Smoke In The Work-Place* by Martin Dewey. This 112-page book identifies cigarette smoke as an industrial health hazard and offers suggestions on how to obtain a smoke-free environment. Examples of success stories are offered as well as suggestions for alliances with unions, fellow employees and government agencies.

Individual copies are available for \$8.95 plus \$1.50 for shipping and handling from NC Press Limited, 31 Portland Street, Toronto, Ont. M5V 2V9.

Women and Reproduction

The second issue of the *Canadian Journal of Women and the Law* examines the relationship between technology, reproduction and the rights of women, children and men. Issues such as forced pregnancy, in vitro fertilization, artificial insemination, disabled rights, reproductive injuries and children's surnames are discussed.

The journal is published twice a year. The subscription cost is: students/low income, \$20.00; individuals, \$35.00; institutions, \$60.00. Outside Canada add \$5.00 for each year's subscription. Single copy rates are

Contact the *Canadian Journal of Women and the Law*, 323 Rue Chapel Street, Ottawa, Ont. K1N 7Z2. (613) 238-1545.

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