

THANKS TO YOU HEALTHSHARING IS STILL ALIVE AND KICKING!

Summer, 1990
\$3.00

Healthsharing

A CANADIAN WOMEN'S HEALTH QUARTERLY

DisAbled Parents

Enjoying motherhood and
overcoming stereotypes

Hysterectomy

The most common surgery
performed on women
in Canada

Patients' Rights

An agenda for the 1990's

AC0488
SHEILA RAINONEN
June 01/92
134 SHERBURN ST
WINNIPEG, MB
R3G 2K4



INSIDE

Vol 11:3

June, 1990

Collective Members
Susan Elliott, Amy Gottlieb, Lisa McCaskell, Monica Riutort

Administration
Amy Gottlieb, Megan Williams

Advertising
Susan Elliott

Circulation/Promotion
Amy Gottlieb

Copy Editing/Proofing
Lisa McCaskell

Design/Production
Susan Elliott (coordinator), Heather Bell, Katie Pellizzari

Editorial
Amy Gottlieb (coordinator), Jo-Ann Minden, Megan Williams

Typesetting
Cyndra MacDowall/ArcheType

Printing
Delta Web Graphics

Cover Photo
Amy Gottlieb

Editorial, Advertising & Subscription Offices
14 Skey Lane, Toronto, Ont. M6J 3S4
(416) 532-0812

Published quarterly by Women Healthsharing, Inc. Anyone wishing to make a tax-deductible donation (\$10 or more) please send a cheque payable to Women Healthsharing.

Subscription rates are \$12/year, individuals; \$24/year, organizations and institutions. USA add \$2 Cdn or US funds; other add \$3, International Money Orders only.

Women Healthsharing endeavours to print material with which we agree; however, not every article or column reflects the opinion of all collective members or of our funders.

Authors and artists retain copyright, 1990. No part of this magazine may be reprinted without prior permission. Unsolicited manuscripts or artwork should include a stamped self-addressed envelope. A writing guideline is available upon request.

ISSN:0226-1510. Second Class Mail Registration: 5327.

Advertising rates are available upon request.

Indexed in the Canadian Magazine Index and the Alternative Press Index and available on-line in the Canadian Business and Current Affairs Database. Printed in Canada.

FEATURES

12 Don't Ask Your Gynecologist If You Need A Hysterectomy...
The conspiracy against the uterus
Zelda Abramson

20 A Different Parent
DisAbled parents overcome stereotypes
Karen Blackford

ALWAYS IN HEALTHSHARING

3 Collective Notes

5 Letters

8 Update

18 My Story, Our Story
Searching for an Alternative to Hysterectomy
Heather Tucker

25 Healthwatch
Patient's Rights, An Agenda for the Nineties
Maggie Burston

28 Resources and Events



CHART A

Dawna Gallagher

COLLECTIVE NOTES

We Will Not Be Silenced!

H *healthsharing* is facing the most critical moment in its history. The Tories have dealt us a serious blow, along with many other women's organizations, aboriginal and multi-cultural groups. This attack on critics of government policy is an attempt to silence those who work on behalf of the majority of Canadians for social justice and equality.

It is an attack that the government calls "deficit reduction." As Mary Collins, Minister Responsible for the Status of Women wrote us, "there is no painless way to implement the spending reductions required to cut the national deficit in half by 1993-94." How moving! Why not describe the "pain" the Conservative government felt as it spent \$14 million to promote the Goods and Services Tax (GST) or as it gave Boeing a gift of \$161 million - the money cut from the Secretary of State Women's Program over the past two years amounts to 2% of this handout! And by altering the tax structure in 1985 to further benefit corporations, the Tory government has forfeited an estimated \$8 billion to date - \$1 billion more than last February's budget cuts! This is not deficit reduction. This is an attack on our ability to communicate, educate and organize.

Slashing federal funding to feminist advocacy, education, research and publications is a life threatening blow which is compounded by health and social service cuts and the pending burden of the GST. These budget cuts herald a new public policy. Even more drastic funding cuts are likely and will affect not only women and aboriginal groups but all groups working for justice and equality.

But we take heart in the Tories' record low standing in the polls for five straight months. And we know that it was women's militancy and actions in response to the budget cuts that forced the government to

reinstate funding to the women's centres for one year. All the organizations that had their funding slashed received tremendous support across the country. Women came out to occupy Secretary of State offices, to demonstrate and challenge the government on its abysmal record on women's equality. We said loud and clear that the budget cuts will never silence us and that our movement is strong and diverse.

The heat and militancy of those protests needs to continue. The government's hat trick has worked temporarily. By reinstating funding to women's centres for one year, the Tories are banking on shutting us up, on confusing our supporters. We won't be silenced, even knowing we're unlikely to wring more concessions out of the government this legislative session. Women in alliance with aboriginal people and other communities, must keep up the pressure. We believe that the Canadian government has an obligation to use public funds to fund organizations working for social and economic change. We must keep our issues on the agenda. First nations people in this country were able to stop Meech. Through our combined strength we can defeat future deficit cutting measures and bring down the government.

A major campaign, the Banner Project, will provide women across the country with a forum to tell the truth about the conditions of their lives and challenge the government's self-congratulatory praise for its record on women's equality. (see page 4).

The three national publications that were cut, *Resources for Feminist Research*, *Canadian Women's Studies* and *Healthsharing*, face an uncertain future. No other level of government seems willing to provide core funding to feminist periodicals. This comes at a time when Canadian periodicals are already vulnerable, because of the

implementation of the GST, the threat to postal subsidies and difficult marketing conditions in this country.

So, where does this leave *Healthsharing*? One thing we know for sure, we're still alive and kicking, thanks to the generous support of our subscribers. We still remain committed to the vision of an equitable and accessible community-based health care system - a system that addresses the social and economic realities of people's lives, a system that focuses on prevention, a system in which women are respected as the experts on our bodies.

For the past four months we have been actively pursuing other government grants. In what we considered to be our best chance, we applied to the Ontario Ministry of Health but were refused funding because the provincial government won't fund magazines. (We were told we could receive money if we wanted to be something other than a magazine.) We have received a similar message about the unavailability of core funding for our magazine from other levels of government. In addition, we are excluded from provincial and federal art council funding because our focus is health.

Does this mean we will have to fold? We hope not. Our plan is this: we are committed to publishing at least another two issues, both thematic - the delayed issue on immigrant and refugee women's health and an issue on menopause. We will continue both our government and private sector fundraising efforts. With volunteer labour we can survive in the short-term, but we need emergency funds to give us time to do long-term fundraising and reorganize for the future.

Thank you for your support over the past four months. We have received an outpouring of letters and financial contributions (over \$10,000!) from you, our readers, which has enabled us to survive, given us time to seek other funds, organize against the Tory cuts and plan for the future. Once again we are turning to you, our most loyal supporters to help us through this difficult period. Let's keep one of Canada's vital health resources alive.

Susan Elliott, Amy Gottlieb, Lisa McCaskell, Monica Riutort.

The Banner Project: Speaking the Truth About Women's Lives

What is the Banner Project?

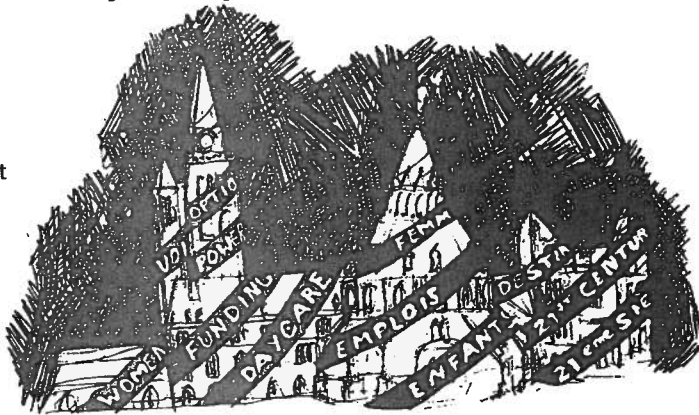
Across the country women have taken to the streets to tell the Tory government that budget cuts won't silence us. Now we're going to Ottawa. The Banner Project is a chance for women's groups across Canada, of whatever size, to let the government know what is really going on in our lives.

We are asking every women's group in the country to produce a protest banner. You might want to illustrate the experiences of women in your community with sexual harassment, low wages, racism, poverty or homophobia. Your banner can have pictures or words or both. Use your imagination! Create your own reality!

We hope that women across the country will hold their own actions to display their banners. Then they will be collected and taken to Ottawa by regional representatives. There we will form one huge banner that we hope will be big enough to tie up the Parliament Buildings!

When Will It Happen?

Tying up Parliament will coincide with the Third Commonwealth meeting of Ministers Responsible for Women's Affairs, scheduled to take place in Ottawa, October 8-11, and with the



L. Emily Elliott

twentieth anniversary of the Royal Commission on the Status of Women.

Why Are We Doing It?

Cutbacks

Federal budget cuts have eliminated or reduced social services and programs for women. Groups speaking out on behalf of women and voicing opposition to government policy have also suffered devastating cuts. *The Government Does Not Consult with Women's Groups* The Canadian government seems to be proud of what it has done for Canadian women. It makes presentations at international meetings about Canadian women without ever having asked us what our situation is. These reports are self-congratulatory lists of government legislation and spending, with little or no reference to what we know are the real difficulties faced by Canadian women.

Solidarity

We want to show the government the strength of women across the country working together in solidarity. We want to challenge its cynical treatment of us and our programs.

Our nationwide protests embarrassed the government into providing some "transitional" funding for women's centres, but it is not enough. We suspect the government intends to continue these cuts. We think it will eliminate the Secretary of State Women's Program altogether, when just three short years ago this government reaffirmed its commitment to the Women's Program in its own Fairness in Funding report.

We want to hold the government to its supposed commitment to equality for women.

How to Make Your Banner

Your banner must be four feet high, but can be as long

as you like (eight feet is probably a good length). Use a strong material for the background so that it will not rip when tied to other banners, and attach four 10"-12" long ties 16" apart along both ends so it can be joined to the others. Don't forget to put your group's name on the banner. Have fun!

Due Date

Your banner should be completed by September 15 and delivered during a local or regional celebration to your regional contact by September 22.

Who to Contact

We're hoping that women all across the country will take on the responsibility of organizing the Banner Project from their area. This will include: getting the word out to as many organizations as possible; coordinating a regional banner celebration; local fundraising to get banners and women to Ottawa; collecting and sending banners to Ottawa; liaison with Banner Central in Ottawa.

Contact the National Action Committee on the Status of Women representative in your area or *Healthsharing* for further information. And let's get out there and make those banners.



Smokefree

Teaches Women to Quit Smoking

(416) 465-1323

Phyllis Marie Jensen, R.N., Ph.D.

also FEMINIST PSYCHOTHERAPY
and DREAM ANALYSIS

MICHELINA PALLOTTA BELLICOSO
M.S.W., C.S.W.

Individual, Couple &
Incest Group Counselling

517 College Street
Suite 410
Toronto, Ontario M6G 4A2

Telephone (416) 929-1816

LETTERS

We encourage readers to write. Your comments and criticism are just as important as the original articles and columns published in the magazine. Please take the time to share your opinions with other readers.

Healthsharing reserves the right to edit letters for length, and print them, unless they are marked "not for publication."

Wholehearted Support

We applaud you for the tremendous work you have done to date and wholeheartedly support you in your struggle to keep *Healthsharing* alive. *The Toronto Women's Health Network*
Toronto

Unique Focus

I was dismayed to learn that the Canadian government is discontinuing its support of *Healthsharing*. As a citizen of the United States, I obviously have no power to influence Canadian policy-makers. Nonetheless, I want to add

my voice to those of your readers around the world who will sorely miss *Healthsharing* if you are forced to cease publication.

For over a decade, *Healthsharing* has presented a critical feminist perspective on women's health issues. It is not alone in this; *Health Care for Women International* and *Women and Health* both deal with the same broad subject. Unlike these other periodicals however, *Healthsharing* is aimed not at medical practitioners but at health care consumers. In this very valuable focus, it is unique. The articles in *Healthsharing* are models of clearly written prose; the information is up-to-date; and the reader is encouraged to seek out more information by the inclusion of resource lists and reviews.

My office is quite selective in its coverage of non-U.S. publications in our quarterly, *Feminist Periodicals: a Current Listing*

of *Contents*. However, we have never questioned the inclusion of *Healthsharing*, because it fills a unique niche in the array of women's information sources. I have had numerous occasions to recommend your magazine to U.S. undergraduates engaged in research on women's health.

I hope the Canadian government can be persuaded to reinstate at least some of your 1990/91 funding and that your fundraising campaign will be a success.
Susan Searling
Madison, Wisconsin

Wonderful Emotional Experience

I sat and read your article "A Natural Resource" by Leslie Ayre-Jaske (*Healthsharing*, Spring 1990) while I was breastfeeding my 6 1/2 month old daughter.

I am very happy that you are supportive of breastfeeding, as I have found it a wonderful emotional experience as well as much easier than making formula. But I must say that my experiences have not been like those described in the article.

While in the hospital after delivering my baby the nurses were informative, helpful and very encouraging to get me to learn how to feed my baby. It's so important to remember that both the mother and the baby have to learn the process. The hospi-

tal nurses also provided creams to help avoid sore nipples and instructions about how to latch on...I have since managed to feed my daughter in places all over Manitoba, in restaurants, malls, offices, etc. I have never been asked to leave or even been made uncomfortable.

I have a question about the use of "certified lactation consultants" in helping women to breastfeed. It seems to me that this is just another specialist like the medical profession to "denaturalize" the experience. I think the best people to offer information and support to women who breastfeed are other women who have breastfed.

I have found breastfeeding one of the pure joys of motherhood and I wish more women could experience it as I have. Let's hope that begins to happen.

J.E. Park
Portage la Prairie, Manitoba

Frequently Made Errors

The Collective Notes "Addressing the social causes of health" (*Healthsharing*, Spring, 1990) is an important article and I must commend you for it, as well as many others published in *Healthsharing*.

However I must draw your attention to two frequently made errors - even by persons in health care

COOKING ON A SHOESTRING

Cooking
on a
shoestring

Nutritious and economical, over 250 meatless recipes in easy to follow steps.



Send cheque or money order for \$12.50 to:
M. Duhamel Creative Enterprises Company
P.O. Box 39119-HS, 235 Dixon Road, Weston,
Ontario M9P 3V2

MASSAGE THERAPY

In the comfort and convenience
of your own home

Learn to relax and combat stress naturally

Registered Massage Therapist
3 Yrs Clinical Experience

For appointment or consultation

Call 423-7576

Chris M. Godi RMT

professions. You write "health prevention" twice, when I believe you mean "health promotion."

"Disease prevention" is correct. The whole aim of your article is "health promotion."

*Cora Hinds
Ottawa, Ontario*

Stronger Reply Needed

I was listening to the radio (CBC) this morning when I heard Amy Gottlieb discuss how the government funding to the magazine was slashed \$60,000. I used to subscribe, have moved several times, but have always found an issue to read at a friend's...as Amy said, those 4,800 subscriptions translate into 12,000 readers.

Besides renewing my subscription, I want to say how disappointed I was by the interviewer. When she said "Why should I read this magazine?" in a condescending tone, I would have replied much more strongly than Amy and said "When they want to do a total hysterectomy that you don't feel you need, there will be resources you can turn to for support, emotional and physical, or when you decide to have a child and want to compare advantages of home birth to that of the hospital, etc..."...where would she be today without all of us sisters busting our butts, sup-

porting each other through our work?

*Nettie
Toronto, Ontario*

Encouraging Self-responsibility

As a current subscriber and supporter of your magazine, *Healthsharing* has been so instrumental for me in encouraging self-responsibility and greater awareness of personal health issues. Most recently, your articles "Healing from Within" and "Dear Dr. M" (*Healthsharing* Winter, 1989) stand out for me as being powerful personal accounts of women's process of empowerment to heal and question the patriarchal Western medical model.

I will continue to support your magazine and spread the word to all my women friends. Keep up the wonderful and outstanding work in the midst of government restraint.

*Eva
Etobicoke, Ontario*

Outraged

I was outraged to learn that the federal government has cut your funding. I believe in the work you do and have decided to buy a subscription in lieu of picking *Healthsharing* up from my local women's bookstore. Thank you for an informative and excellent women's

publication.

*L. Schmidt
Vancouver, B.C.*

Vicious Cutbacks

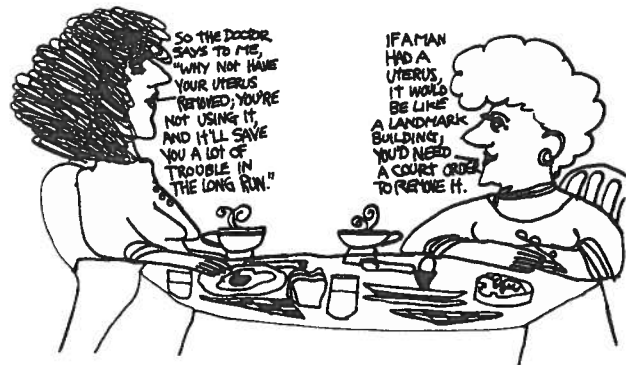
We share your outrage with regards to the federal government's vicious cutbacks and are deeply concerned about your survival. Canada's feminist community cannot afford

you are no doubt feeling even more enraged than I. I am happy to hear that you are going to try and find funding elsewhere.

*Maureen Gans
Toronto, Ontario*

Enraged

I understand that the federal grant allocated to



*Nicole Hollander
I'm in Training To Be Tall and Blonde*

to lose you. Meanwhile, although we ourselves are far from basking in an envious financial situation, we are one of the lucky feminist publications that has not (yet?) been attacked.

*Atlantis
Halifax, N.S.*

Anger and Frustration

We would like to express our anger and frustration at the recent government cuts which affect *Healthsharing*. Our community in rural Nova Scotia benefits from publications such as *Healthsharing* being in our resource centre.

*Pictou County Women's Centre
New Glasgow, N.S.*

Absolutely Livid

I am absolutely livid about the funding cutbacks that are putting *Healthsharing* in the possible position of shutting down. I could sputter on and on about the gross injustice of all of this to women's programs in this country...needless to say,

Healthsharing is about to be terminated. As a single woman who pays a substantial amount of tax each year this enrages me. My taxes are being used to support programs of which I do not approve i.e. military programs, etc.

I am a health professional working within a system that is largely traditional, anti-feminist and autocratic. Change is being made but it is very slow. *Healthsharing* is a precious catalyst in bringing about that change. We can't afford to let *Healthsharing* go!...I read every issue from cover to cover. It brings me both personal and professional pleasure. I use it as a resource in my practice and share it with other women. Buying *Healthsharing* for me is a ritual...Each issue has valuable experiences and resources shared in it. It is women talking to women about one of our most treasured resources - health.

*Joanne Fitzgibbon
Whitby, Ontario*

WOMEN TOGETHER IN EARLY MENOPAUSE

A six week information and support group for women experiencing an earlier menopause (under 42 years of age)

Beginning mid-September 1990

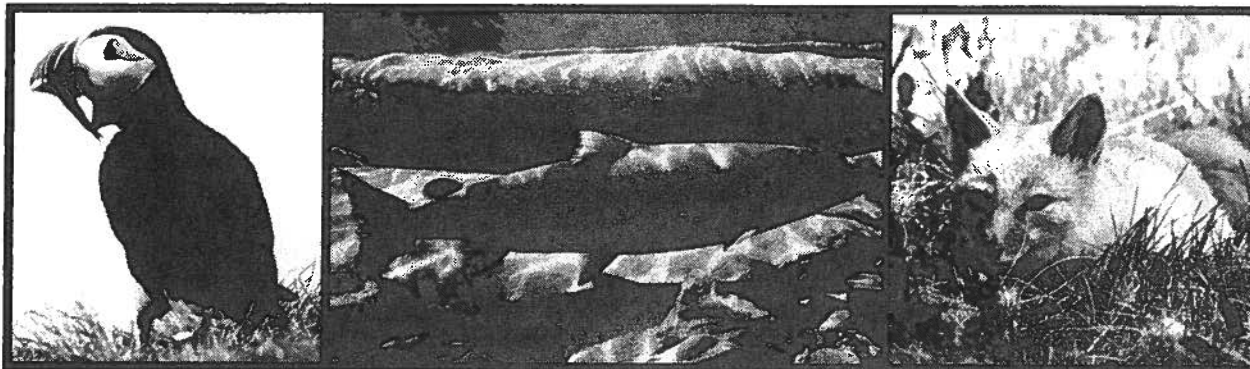
For further information call:
Zelda Abramson
College Street Women's Centre
929-1816

From the National Film Board of Canada

A GUIDE TO RECENT AND UPCOMING FILMS AND VIDEOS
ON ENVIRONMENTAL ISSUES:

THE NFB ENVIRONMENTALIST

for ENVIRONMENTAL and PEACE organizations, TEACHERS (peace educators, secondary science and social sciences) PUBLIC LIBRARIANS, CHURCHES and other COMMUNITY GROUPS



The National Film Board is committed to supporting critical thinking about environmental and ecological issues and promoting positive social action in response to environmental problems.

For this reason, the NFB has published **THE NFB ENVIRONMENTALIST**, a guide to some of our most recent, relevant and thought-provoking films and videos on a wide range of environmental issues:

**ACID RAIN / URANIUM MINING / TOXIC WASTE / GROUNDWATER POLLUTION /
HERBICIDES and PESTICIDES / ECO-FEMINISM**



National Office
Film Board national du film
of Canada du Canada

I'd like to know more about NFB environmental films and videos.

- Please send me THE NFB ENVIRONMENTALIST.
- Please add my name to your mailing list to receive information on new releases and send me a copy of your video rental catalogue.

NAME _____

INSTITUTION _____

ADDRESS _____

CITY _____

PROVINCE _____ POSTAL CODE _____

**MAIL TO:
NFB Community Market
Development Group, D-5
P.O. Box 6100, Station A
Montreal, Quebec
H3C 3H5**

UPDATE

Our turn

Last November, about one hundred and fifty psychiatric survivors met in Montreal for a national conference entitled Our Turn. The two and a half day conference featured a panel of internationally known activists, including Judi Chamberlin (National Association of Psychiatric Survivors, U.S.), Louise Pembroke (Survivors Speak Out, Britain) and Hans Weigant (Holland). Workshop topics included

poverty, medications, women and madness, building alternatives and local organizing.

Because survivor organizing has been relatively fragile and uneven across Canada, and regional concerns differ, there were several heated debates on the conference floor. It was argued that referring to oneself as a mental health "consumer" sounded defeatist, whereas the term "psychiatric survivor"

identified one's experiences as a political struggle against poverty, sexism, racism and heterosexism. Others openly challenged the role of groups like the Canadian Mental Health Association, viewed by some as a source of potential partnership, by others as a source of inevitable co-optation. Activists were in two camps; those who were less critical of the "medical model" approach and those who were fiercely opposed.

The forum took on an energy of its own. Two and a half days was not enough. To maintain momentum, participants struck up a tentative committee to organize next year's conference and to build a network to support one another in what may be uphill battles in local

organizing. Participants suggested we call ourselves "National Union of Transatlantic Survivors," or NUTS for short.

Since then, Ontario participants have been getting together to organize an Ontario group that will be a voice for psychiatric survivors. We call ourselves the Ontario Psychiatric Survivors' Alliance (OPSA). We struck a steering committee, started a newsletter, applied for funding and have begun to speak out on many issues that affect us. For more information, contact Irit Shimrat, Coordinator, OPSA, 3107 Bloor St. West, Suite 201, Etobicoke, ON, M8X 1E3 (416)234-9245.

ANGELA BROWNE

The dark side of white

The Women's Environmental Network has launched an international campaign to highlight the problems associated with chlorine bleaching of soft paper products. The adverse effects of making paper products whiter-than-white has been well documented in Canada. In September 1987, the Canadian pulp and paper industry acknowledged that dioxin and organochlorine compounds could be found, not only in the waste effluent from the mills, but also in the products themselves.

Tests in the United Kingdom by the television program World in Action found measurable quantities of dioxin in sanitary napkins, tampons, toilet paper, coffee filters and food packaging. The British public was told that it had asked for white paper and

was therefore responsible for the environmental and health problems associated with its production. But as soon as it became clear that a creamier shade of white meant less pollution, consumers began to switch to the unbleached paper. The Women's Environmental Network received 50,000 letters asking for more information and the British Department of the Environment claimed they received more letters about diapers than any other environmental issue that year.

But what happened in Canada? While Europe was discussing the "Nappy War" as one company after another spent millions trying to prove how eco-friendly they were, Canadian manufacturers stalled. Only one company has an



Angela Martin / Women's Environmental Network

unbleached diaper and sanitary napkin and the sales of these products definitely reflect growing consumer interest.

The industry is quick to point out that levels of dioxin found in consumer products are very low, too low to pose a serious health hazard, even though a 1988 Canadian study found that dioxin is able to travel through plastic in milk cartons and into the milk.

Studies on bleached coffee filters found dioxin in the coffee. The debate still rages about how much or how little can be absorbed through the skin from a variety of products. However, the continued production of chlorinated paper is causing massive environmental damage, destroying ecosystems and filtering organochlorine compounds into our air and water.

What can you do? Switch to reusable, washable and recyclable materials. Insist on unbleached or chlorine free paper products. Show the pulp and paper industry that producing whiter-than-white paper is no longer desired or acceptable. Fact sheets on the Canadian pulp and paper industry and dioxin are available from Greenpeace, 578 Bloor St. West, Toronto, ON, M6G 1K1.

BERNADETTE VALLEY
LONDON, ENGLAND

Cervical cancer and smoking

While it's commonly known in Europe that cervical cancer is caused by a sexually transmitted virus, it has only recently become more widely known in North America (This Magazine, May-June 1989). Now a Montreal specialist has linked smoking to the development of the human papilloma virus (HPV), which causes cervical cancer. Alex Ferenczy, professor of pathology and obstetrics and gynecology at McGill University, says smoking is a co-factor in the development of the disease. He believes that the virus alone may not be enough to cause cancer and strongly recommends that any woman who has had

abnormal pap smears should quit smoking.

"For every cigarette a woman smokes, her cervix smokes ten," he says, adding that carcinogens from cigarettes show up in cervical secretions in ten times the concentration they do in blood. Nitrosamines, present in cigarette smoke, are known to cause cancer in the lungs and esophagus. Since the cervix is made up of similar squamous cells, women who smoke double their risk factor for cervical cancer.

The Virapap test, which detects the HPV virus in men and women, is now available. It's important that men as well as women be checked, since, according to

Ferenczy, 70 per cent of the lesions that the virus causes in men cannot be seen by the naked eye.

The HPV comes in a wide variety of strains, differing in degrees of malignancy. While genital warts caused by the virus are often benign, a man who has them may well harbour one of the more virulent strains too. Those believed to cause cancer are types sixteen and eighteen, as well as all types with numbers in the thirties and fifties. Ferenczy says the male partners of women exhibiting virulent strains should be examined and, where possible, treated. While Ferenczy and other specialists familiar with this condition often counsel

such men to remain monogamous, their female partners must continue to have regular pap tests.

Since the HPV behaves like most other viruses, there is always the possibility that a woman or man who has been treated will continue to harbour the virus. Once a virulent type has been confirmed, regular check-ups are essential. Using a barrier method is a way to increase your chances of avoiding the virus in the first place.

"You could give up sex," Ferenczy notes drily, "but that would be very boring."

ALISON DICKIE
REPRINTED FROM *THIS*
MAGAZINE, JUNE, 1990

An experience that lasts a lifetime.



Barbara McCann, CUSO

CUSO NEEDS

- **OCCUPATIONAL THERAPISTS**
for Zimbabwe and the Solomon Islands.
- **PHYSIOTHERAPISTS**
for Thailand, Nigeria and Bangladesh
- **HEALTH EDUCATORS**
for Nigeria and Togo
- **NURSE MIDWIVES**
for Ghana
- **NURSE TUTORS**
for Papua New Guinea

CUSO offers you a challenge. The chance of a lifetime. Two years of living in another culture and an opportunity to work with others who are striving to improve their lives.

We need someone special. Someone who wants more than 9 to 5. Someone willing to try something different.

If you have skills and experience and can live on a modest salary, we may have a job for you.

Join other Canadians working in the Third World. Join CUSO.

For further information send your résumé to:
**CUSO DH-3, 135 Rideau Street,
Ottawa, Ontario K1N 9K7**

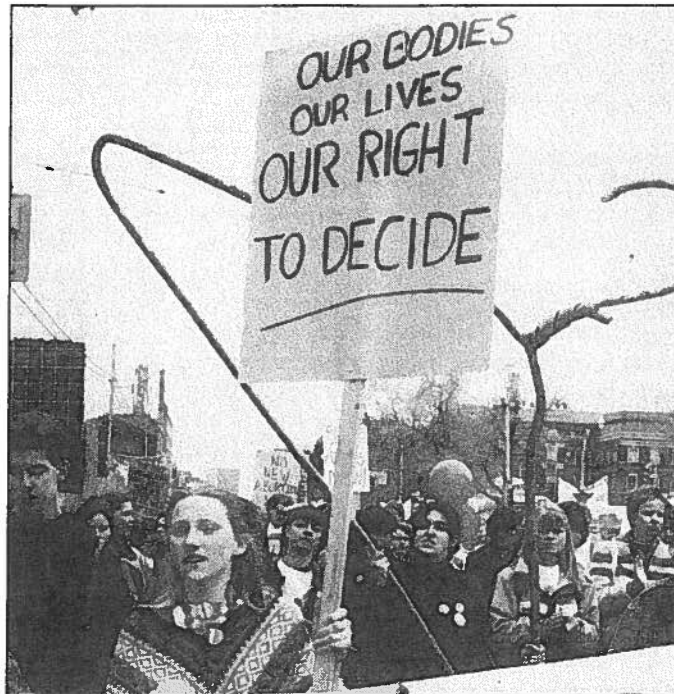


Women lose freedom of choice

Amid noisy protests from pro-choice supporters, MPs voted on May 29 to turn the clock back on women's rights. The House of Commons passed Bill C-43, the act that puts abortion back in the Criminal Code, by a vote of 140-131. (The old law had been overturned by the Supreme Court in January 1988.) The new law will make abortion illegal unless a doctor judges that the woman's mental, physical or psychological health is threatened.

When the legislation was first introduced, the Pro-Choice Action Network, a coalition of activist groups from across the country, predicted that it would have a chilling effect on women's health. Unfortunately, the disastrous effects of the bill are becoming clear even before the final Senate vote. On the weekend before the House of Commons vote, a man was charged with performing an abortion on a 16 year-old girl in Kitchener-Waterloo - was this the first result of the panic created by the bill? Regional public health officials expressed grave concern that "back-street abortions" could increase as a result of the legislation. Dr. Janet Ames, Waterloo Region family planning physician, noted that the incident places "stunning" focus on concerns raised by opponents of the proposed new law. She was quoted as saying that "it takes us back to 1969... That's when about a third of the intensive care unit beds were filled with botched abortions."

An even greater tragedy followed. A 20-year old Toronto woman died from a self-induced abortion,



Left Eye

apparently with a coat hanger.

The effect of the proposed legislation on health care providers has already been felt. Fearing prosecution, doctors at the hospitals in Winnipeg and Halifax that provide almost all abortions in their provinces have declared that they would stop. Some began to cancel appointments. The main hospitals in Calgary and Edmonton are also planning to stop providing abortions. These hospitals provide services beyond their immediate areas and these cutbacks will be devastating for women from smaller communities or rural areas and from regions where access to abortion is non-existent. In Ontario, Brantford General, which was the only hospital in the city performing abortions, announced doctors will no longer perform the procedure. The decision was made "out of concern that proposed federal legislation

will leave doctors who perform abortions open to criminal charges".

Whatever the likelihood of doctors being convicted, their real fear is the adverse impact on their reputation and livelihood if they are investigated or charged. And, of course, anti-choice leaders have already promised to use the law to prevent women having abortions.

Even where doctors and hospitals don't stop providing abortions altogether, they may require women to have additional psychological assessments or sign waiver forms attesting to their state of health. Doctors will practice "defensive medicine" - to avoid liability rather than to enhance and facilitate the well-being of their patients. Women face greater bureaucratic hassles and increased delay, which is in turn associated with a higher risk of complications.

Justice Minister Kim Campbell says that doctors

need only practice according to accepted professional standards. Perhaps what she really means is the common practice of doctors telling women what is good for them. She clearly does not mean what should be standard practice for health care providers: providing information on available options and facilitating women making their own choices about the care they need. The idea of restricting abortion through arbitrary health criteria is outrageous and insulting. Being forced to carry an unwanted pregnancy to term is always a threat to a woman's well-being.

What this bill is really about is women's independence and well-being. Abortion is one of the most immediate - and therefore hotly contested - mechanisms of state regulation of women's reproduction and sexuality.

The fundamental political message of this legislation is that women will not be allowed to control their bodies and their lives. In the context of cut-backs to women's centres, publications, research and advocacy groups and attacks on the National Action Committee on the Status of Women, this government is saying, loud and clear, that it will not accept policies and programs that seek to empower women. And this is why we can't give up the struggle.

We must not be demoralized because the bill passed in the House of Commons. We did not lose the vote because of poor strategy or weak organizing. Thousands of people took to the streets to support choice on abortion. This popular support was never clearer than in the months before the vote: on May 12, 1990 there were demonstrations and actions

of one kind or another in communities across the country and there were dozens of actions in the week before the vote. This bill certainly did not pass because of popular support.

We lost this vote simply because there is a majority of Tories in the House of Commons. There were 9 more Tory MPs - and a few Liberals - who voted for their own narrow moralism or caved into the pressure from the Conservative government to toe the line.

The task of the pro-choice movement is to build on this legacy of activism and the solid popular support for women's right to choose. We are still demanding that the law be withdrawn before more women are killed or maimed. If it does come into force, the new law will be challenged in court. We hope health care providers will follow the inspiration of the Quebec clinics that have declared that they will defy its provisions.

The Pro-Choice Action Network and the Canadian Abortion Rights Action League are planning a cross-country series of coordinated actions for free and equal access to abortion on October 13, 1990.

The Pro-Choice Action Network is mounting a major research effort to document and analyze the crisis of access. We need local groups to collect this vital information. To get in touch with your local pro-choice group on how to get involved in building the cross-country demonstrations contact the Pro-Choice Action Network through the Ontario Coalition for Abortion Clinics, (416) 969-8463.

B. LEE

Who do we think we are

"Who Do We Think We Are: Self Image Symposium 1990" was the title and theme for the first national symposium of DisAbled Women's Network (DAWN), held in Toronto last May. DAWN Canada brought together women with all types of disabilities from every region of Canada including the Yukon and the Northwest Territories. As well, non-disabled women from government, women's groups and self-help groups attended. DAWN provided braille agendas, French and English sign language interpretation, oral translation, French and English translation and 24 hour support care. We really tried to make this event accessible to all the delegates.

For four days disabled

women shared their experiences with each other and with the non-disabled women in attendance. Workshops were held on self image, violence, disabled mothers, reproductive technology, legal issues, health and self defense. In several workshops such as the one on abuse and suicide, women shared their pain and survival techniques. In addition to the workshops there were caucuses. HIV positive women, disabled lesbians and straight women who wanted to understand lesbian issues all held caucuses and the reproductive technology workshop continued as a caucus. The symposium was

empowering to all the women who attended.

This first national symposium of DAWN Canada was a very important event. Both disabled and non-disabled women came together and had an opportunity to talk about disabled women's issues. By sharing experiences we learned from each other. Many of the delegates, now back in their local areas, are working on issues that were discussed at the symposium. For more information contact DAWN Canada, 4 Warner Avenue, Toronto, ON, VOICE or fax (416) 288-8147.

PAT ISREAL

AIDS and sexual assault

The AIDS virus is very fragile and is easily killed by contact with nonoxynol 9, the active agent found in spermicidal jellies and foams. A recent article appearing in the Journal of the American Medical Association recommends that women who have been raped apply a spermicide containing nonoxynol 9 as soon as

possible after the attack, before the virus has a chance to enter the blood-stream. Studies show that nonoxynol 9 will not affect evidence needed to pursue legal action. DNA, the genetic information extracted from sperm which can be used to identify the rapist, can still be found up to five days after using nonoxynol 9.

Although both the Rape Crisis Centre and Hassle Free Clinic in Toronto agree with the American Medical Association and would recommend the use of a spermicide after a sexual assault if the woman is fearful of infection with the virus, they emphasize that such action would be more for psychological reasons than medical ones. Given that less than 40% of rapes involve the transmission of body fluids (ie. ejaculation into the woman's body), it is rare that AIDS is contracted through rape. Nonetheless, the application of nonoxynol 9 may alleviate the fear of HIV infection many women feel following a rape and will eliminate any possibility of HIV transmission.

MEGAN WILLIAMS

THE CHILDBIRTH PICTURE BOOK (CBPB)

"A Picture Story of Reproduction from a Woman's View" by FRAN P. HOSKEN. Drawings by MARCIA L. WILLIAMS with TEXT, LEADER'S GUIDE, GLOSSARY, RESOURCE LIST.

The **BASIC CBPB** - for USA Readers



The **UNIVERSAL CBPB** - English / French / Spanish / Arabic
--for Community Health Workers world-wide
LIST PRICE \$ 7.00 /Book - One Sample \$ 4.00

CBPB FLIP CHART. CBPB COLOR SLIDE PROGRAM
- for Group Meetings / Education Programs

Order from: **WOMEN'S INTERNATIONAL NETWORK**
187 GRANT STR. LEXINGTON MA 02173. USA.

Zelda Abramson

Don't Ask Your Gynecologist If You Need a Hysterectomy...

A woman asking her gynecologist if she needs a hysterectomy is like a man asking his barber if he needs a shave. The answer is all too likely to be "yes" whether it is needed or not. Hysterectomy is the most common surgery performed on women in Canada today, in part because doctors fail to consider more conservative alternatives. This approach is deeply embedded in the history of gynecology.

The first successful hysterectomy, removal of the uterus only, was performed in Massachusetts in 1853. However, it was oophorectomy, the removal of ovaries or castration, which became the most popular gynecological surgery between 1880 and 1910. At this time, the field of gynecology provided treatment primarily for "female personality disorders." It was believed that a woman's ovaries controlled her personality and that any psychological problem - from irritability to insanity - should be treated by gynecological surgery.

Gynecologists also expressed deep concern over women's "uncontrollable" sexual desires and to cure this problem, castration was recommended and executed. Sexual transgressions, masturbation and orgasm were viewed as symptoms of women's mental disorders which in turn were regarded as a function of defective ovaries. Castration for treatment of so-called female personality disorders was still practised as late as 1946.



Katie Pelizzari

Indeed, women's reproductive organs were held responsible for all female disorders such as headaches, backaches, sore throats, indigestion and even tuberculosis. Any symptom could easily provoke a medical attack on her ovaries.

Hysterectomy is the modern day replacement for oophorectomy. Approximately 90 per cent of hysterectomies are performed for non-cancerous reasons. They are performed on women who have fibroid tumours, a prolapsed uterus, endometriosis, hyperplasia with abnormal bleeding, pelvic inflammatory disease, cysts or an obstetrical mishap. An estimated 25 per cent of Canadian women have had hysterectomies compared to 30 per cent of American women and 11 per cent of English women. The rate in Canada is twice that of Europe. Close to 60,000 hysterectomies are performed in Canada each year. The majority are performed on women between the ages of 35 and 44. In fact 63 per cent of all women having hysterectomies are under the age of 45. Removal of ovaries as well as the uterus is a procedure performed in about 50 per cent of women over the age of 40.

It is estimated that half the hysterectomies performed in Canada are not medically necessary. In 1971, the Saskatchewan Ministry of Health commissioned a study examining whether hysterectomies were justified, as a result of a 72 per

cent increase in the number of hysterectomies performed between 1964 and 1971. The results of this study which audited medical charts of five hospitals found that between 17 and 59 per cent of hysterectomies performed were unnecessary. An interesting side effect of this study was that the rate of hysterectomy in Saskatchewan subsequently dropped dramatically.

Between 1975 and 1977, the U.S. House of Representatives held hearings on unnecessary surgeries. Three major surgeries were evaluated to determine whether their prevalence was justified: appendectomy, prostatectomy and hysterectomy. The report concluded that the appendectomy and prostatectomy surgeries were justified, however, over 40 per cent of the hysterectomies performed were unwarranted. A further study reported by the U.S. Department of Health and Human Services in 1983 found that in 48 per cent of the 1,851 hysterectomies studied it was not confirmed that the uterus was diseased.

The Canadian rate of hysterectomy varies significantly from province to province. If you live in Newfoundland you have a 61 per cent greater chance of having a hysterectomy compared to a woman living in Saskatchewan. The rate of hysterectomies performed in eastern Canada (including Quebec) is significantly greater than the rate in western Canada (including Ontario). Not only do rates vary between provinces, they also vary within provinces.

There are no simple answers to account for the dramatic differences between regions. However this data can be used to test various hypotheses that have been suggested to explain such differences.

One hypothesis is that the rate of hysterectomy corresponds to the rate of cancer of reproductive organs. This is clearly not the case in Canada. In fact the provinces with the highest hysterectomy rate, Newfoundland, Nova Scotia and New Brunswick, have the lowest rate of cancer of the

reproductive organs while the provinces with the lowest rate of hysterectomy, Manitoba and Saskatchewan, have the highest rate of cancer.

A second hypothesis is that there is a direct correlation between the number of gynecologists and the number of hysterectomies performed. Again, this is clearly not the case in Canada. Indeed, the opposite is true. Eastern Canada has fewer gynecologists per capita than western Canada, yet hysterectomies are performed at a higher rate. For example, every year in Eastern Canada, between 562 and 615 women out of 100,000 receive hysterectomies. This compares to a range between 377 and 480 out of 100,000 in Canada's western provinces. This means that in Newfoundland a gynecologist performs on average 75 hysterectomies per year while the national average for a gynecologist is 44 (in itself an astounding number).

Other hypotheses that have been offered to explain regional variations based on income, educa-

compared to western Canada.

Religion may be a factor. It is believed that Roman Catholic women have a higher rate of hysterectomy, and there is a higher percentage of Roman Catholics in eastern Canada than in western Canada. One reason why Catholics may have a higher hysterectomy rate is because of their socio-demographic profile. Compared to other religious groups in Canada, Roman Catholics have on average fewer years of schooling, a lower average income and higher unemployment rate. A second possibility to consider is that sterilization by hysterectomy is considered a legitimate form of birth control by this population.

With regard to fee structure, other research has shown that more hysterectomies are performed by fee-for-service physicians than salaried physicians. Medical care in Canada is overwhelmingly provided on a fee-for-service basis. Each province has independent billing schedules, and rates for hysterectomy procedures vary from province to

It is estimated that half the hysterectomies performed in Canada are not medically necessary.

tion, religion and medical fee structures do find support in the Canadian data. Some research has shown that women with lower levels of income and education have a higher hysterectomy rate. For example, a 1986 study of 2000 women in Pittsburgh found that black women with low incomes and education had twice as many hysterectomies as white women who tended to be better educated and have higher incomes.

Eastern Canada is indeed poorer than western Canada. The Atlantic provinces have the highest percentage of families with low incomes. In terms of education, a higher percentage of the population of eastern Canada has less than grade nine education and a lower percentage is in university

province. If we compare the number of hysterectomies per 100,000 in each province to the amount paid to the physician per hysterectomy we find a negative relation: that is, the provinces with the higher rates of hysterectomy pay their physicians the least amount of money for this procedure.

Does financial motivation play a role in terms of numbers of hysterectomies? One physician quoted in the New York Times Magazine in September, 1975, said that since there is a decline in the birth rate, "Some of us aren't making a living, so out comes a uterus or two each month to pay the rent."

If indeed financial motivation is a factor, one solution is to restructure the fee schedule so that more conservative treatments are financially

Glossary

Abnormal bleeding or "dysfunctional uterine bleeding" is the catch-all phrase for undiagnosed heavy bleeding. Many unnecessary hysterectomies are performed because bleeding continues yet there is no pathology.

A number of alternative remedies exist which may or may not work for you. They include: Vitamin A therapy, in combination with Vitamin E and zinc; herbal therapies such as horsetail tea in combination with vitamin B; antiprostaglandins; antihistamines; and hormonal therapy (e.g. progestin and birth control pills).

Elective Surgery is a treatment or operation that doesn't need to be done immediately.

Endometriosis is a chronic condition where tissue which lines the uterus grows in places outside the uterus, generally on the ovaries, fallopian tubes, bladder and rectum. It can be extremely painful, particularly around the menstrual period. Endometriosis is more common in younger women and is a major cause of infertility. Very little is known about the cause of endometriosis. It is believed to be related to the hormone cycle and ovulation. The condition seems to improve with pregnancy and menopause.

The two popular conservative therapies to hysterectomy are hormonal therapy and surgery (both laser and conventional) to remove the pockets of the disease. Hormonal therapy is given to suppress ovulation. There are many side-effects and women experience menopausal symptoms. Vitamins, herbs (B6, folic acid, evening primrose oil, etc.) and food supplements have been helpful to many women. Although hysterectomy and removal of ovaries are the prescribed medical cure it is not always effective.

Fibroids are non-cancerous tumours which can grow on all parts of the uterus: the outer surface; within the walls of the uterus; on a stalk outside of the uterus; or into the uterine wall.

The size of a fibroid varies from microscopic to the size of a basketball. Small fibroids are generally not problematic and many women are not aware they have a fibroid. However, a large fibroid can cause considerable discomfort. Fibroids tend to grow slowly and their growth is stimulated by estrogen. Fibroids therefore shrink or disappear after menopause.

Hormonal therapy can also be used to treat fibroids. Progestin has been effective in shrinking fibroids for some women. A new hormonal therapy, LH RH analogs is presently being researched and appears to be effective in reducing the volume of the fibroid.

Unfortunately when the woman stops this treatment the tumour returns to the original size.

Hyperplasia refers to the overgrowth of the lining of the uterus which most often results in abnormal bleeding. It is believed that hyperplasia is caused by too much estrogen and not enough progesterone. Progestin therapy has proven to be an effective cure for the majority of women.

Hysterectomy comes from two Greek words: "hystera" meaning uterus and "ektome" which means to cut out. Hysterectomy is the removal of only the uterus and not the ovaries. Removal of both ovaries is called a bilateral oophorectomy. Removal of the uterus, fallopian tubes and ovaries is medically referred to as hysterectomy and a bilateral salpingo-oophorectomy (BSO). **Myomectomy** is a surgical procedure which involves only the removal of the fibroid tumour. However, hysterectomy is an easier and less complicated surgery. A myomectomy is more readily available to women in their 30's who are hopeful of having children. If you are over 40 it is difficult to find a gynecologist who will willingly perform this procedure.

Pelvic Inflammatory Disease (P.I.D.) is a bacterial infection in the pelvic region primarily caused by sexually transmitted diseases

such as gonorrhea or chlamydia which have gone untreated. Women who use I.U.D.'s as a method of birth control are at an increased risk. Severe P.I.D. can cause scarring and adhesions in the pelvic organs which can result in infertility. Intense and chronic pain is common with P.I.D.

Early detection and prevention of sexually transmitted diseases can reduce the risks of chronic disease. Antibiotics are effective in treating 80 per cent of cases. **Prolapsed Uterus** is the sagging of the uterus into the vagina. Muscles supporting the uterus become weakened and if sufficient estrogen levels are not present the uterus drops. Women who have had multiple births commonly experience this problem.

Alternatives to hysterectomy include strengthening the pelvic floor muscles by doing Kegel exercise in combination with Hormone Replacement Therapy. Exercise alone will not correct severe prolapse. Hormone replacement therapy helps build muscle mass and can help strengthen the muscle. Pessaries are devices similar to a diaphragm placed in the vagina to hold the uterus in place either temporarily or permanently. Pessaries can be a bother to the woman. They must be taken out and cleaned periodically and the vagina must be examined for irritation. You cannot have sex when wearing most types of pessaries. In cases of severe prolapse, surgery which resuspends the uterus has been reported to be successful. A prolapsed uterus is a progressive condition which worsens with time. The sooner you treat the condition the better your chances of a non-aggressive solution — no surgery.

The alternative suggestions presented are by no means all inclusive and are only meant to illustrate that alternate approaches do exist. Any treatment you wish to undertake should be under the supervision of a naturopath, a homeopath or a physician.

rewarded. Currently, for example, a surgeon receives less money for a myomectomy (the removal of benign fibroids in or on the uterus), a more complex, time-consuming surgery than for a hysterectomy which removes the entire uterus. Logically, most surgeons opt for the best-paid, most straightforward solution - hysterectomy.

Although at this point we can only speculate about why regional variations exist, the very fact that they do allows us to conclude that the decision whether or not to have a hysterectomy for non-life threatening reasons, in the majority of cases, is based on the discretion of the attending physician.

Many diseases of the pelvic region are painful and uncomfortable. Pain and bleeding are often the first two signals of a problem needing medical assistance. Frequently physicians recommend hysterectomies as a cure for these symptoms. However hysterectomies do have serious negative physiological and psychological consequences which women must consider. Hysterectomy is major surgery. The recovery period is lengthy, on average 13 months, compared to four months for other abdominal surgeries (e.g. removal of gall bladder).

In 1984, a study examining the risks and benefits of hysterectomy in Manitoba reported that four per cent of women experienced serious complications requiring readmission to hospital within two years following their hysterectomy. Furthermore, the study noted that although these women visited their gynecologists less often for gynecologic related problems following their surgery, they required medical intervention more frequently than other women for psychological problems, physiological problems and menopause.

Urinary tract problems appear to be a common complaint women have following a hysterectomy. This is indeed ironic as prevention of bladder problems, attributed to fibroids, is one of the most frequently used justifications to recommend a hysterectomy. Other common side-

effects following a hysterectomy are gastro-intestinal problems such as cramping and bloated feelings. Also, internal scar tissue known as adhesions can lead to chronic pelvic pain. Adhesions occur in approximately 50 per cent of women who have had pelvic surgery.

Post-operative depression is two to three times greater among women who have had hysterectomies than among those who have undergone other pelvic surgeries. One study which examined women four years after surgery noted that women who have had hysterectomies are referred to psychiatrists at a rate three times greater than women in the general population. Moreover the connection between depression and hysterectomy often goes unnoticed both by the woman and her physician for years after her surgery and therefore she may receive improper treatment or none at all.

The reasons for the high rate of depression in women who have had hysterectomies are not altogether clear. Depression is prevalent both

appear to have lower levels of tryptophan. Tryptophan is an amino acid produced in the brain which seems, when levels are low, to trigger depression. Levels of tryptophan correlate with estrogen levels: as levels of estrogen increase levels of tryptophan increase; as estrogen levels decrease tryptophan levels follow.

Furthermore, it is believed that the biochemistry of the uterus contributes to the overall well-being of a woman's health and not only to reproduction. Although not scientifically confirmed it is speculated that the uterus produces prostaglandins which may protect against arthritic inflammation. Finally, the uterus may protect against coronary artery disease and therefore a hysterectomy may increase the risk of heart disease.

Women routinely ask what impact a hysterectomy will have on their sexuality. Usually these women are emphatically reassured that the removal of the uterus will in no way affect their sexual pleasure. This is often not the case.

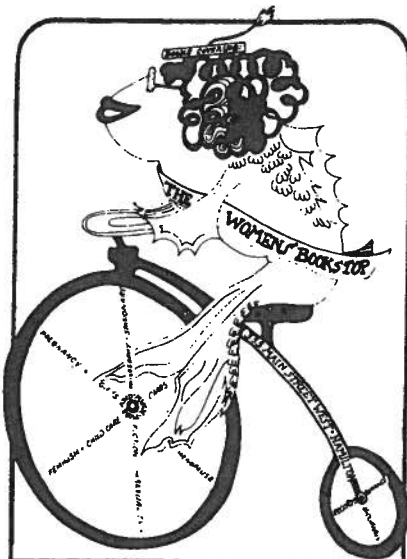
The biochemistry of the uterus contributes to the overall well-being of a woman's health and not only to reproduction.

among women who hoped to have children and did not and among women who do not wish to have more children. For many women the loss of their uterus represents their loss of choice to bear children. Negative changes in body image are common concerns especially when women make a strong connection between their uterus and their femininity.

Many researchers believe that the depression is largely due to neurochemical changes as a result of the hysterectomy. Recent research appears to connect the uterus to the functioning of the body's endocrine system. There is evidence to suggest that the uterus produces and releases estrogen as the ovaries do. Women who have hysterectomies

Many women experience a loss of sexual desire following the hysterectomy. When this occurs many physicians attribute the change to depression. This is WRONG! It is not depression that causes unsatisfying sex, rather the loss of satisfying sex that leads to depression.

There are physiological reasons why women experience difficulty with sex after a hysterectomy. Some women report pain because of a tightened vagina or because of scar tissue in the vagina as a result of having the cervix removed. Whether a woman's orgasm is due to clitoral or vaginal stimulation, the uterus itself plays an important role in sexual arousal and orgasm. As a woman becomes sexually aroused the uterus becomes



333 MAIN STREET WEST,
HAMILTON, ONTARIO
(416) 525-2970
Women's Bookstop

Mothers, Daughters and Breast Cancer

Are you a woman who has had breast cancer? Or has your mother had breast cancer? Would you like to be interviewed for a study on the impact of breast cancer in the mother on the mother, on her daughter, and on the mother-daughter relationship?

If you had breast cancer when your daughter was in her teen years, or if you are a daughter whose mother had cancer when you were in your teen years, and you are willing to be interviewed, please call or write;

Juane N. Clarke, P.H.D.
Wilfred Laurier University,
75 University Ave. W.,
Waterloo, Ontario
Canada N2L 3C5
Phone: 519- 884-1970

Locally, you can contact
Hamilton; C. Nicholson R.N.
416-333-0671
Toronto; J. Levy, M.A.
416-925-1566
Guelph/ Kitchener; S. Allain, B.A.
519-824-9595
519- 824-9595

enlarged and moves around. The uterus is a muscle and during orgasm it contracts at rhythmic intervals. Many women find these contractions pleasurable. Furthermore, blood vessels and nerves which may affect sexual sensation are cut when the uterus is removed.

Studies show approximately 30 per cent of women report improved sex after a hysterectomy. Many of these women experienced severe pain during sexual intercourse before their surgery. Pleasure then was not a consideration. Removing the uterus results in painless sex and thus improved sex, but does not necessarily enhance the woman's ability to achieve orgasm or experience pleasure. These studies do not differentiate between these questions.

The closer a woman comes to the age of 40, the fewer alternatives to hysterectomy are made available to her. For most women under the age of 40, it is easy to persuade the physician to look into alternatives. It is not difficult for

not diagnosed early, there is a poor survival rate. Realistically, the chances of a healthy woman developing ovarian cancer and dying from it is marginally over one per cent. Furthermore, the risk of ovarian cancer does not increase if you choose to keep your ovaries when having a hysterectomy.

Nevertheless physicians continue to justify the removal of the ovaries on the grounds that it prevents ovarian cancer.

The routine removal of ovaries in post-child-bearing women has serious implications for a woman's sexuality. Ovaries continue to produce hormones, specifically androgens, which play an important role in a woman's sexual desire and in her ability to become aroused.

A recent study from McGill University confirms the complaints of many women who have had a hysterectomy and both ovaries removed: decreased sexual desire and arousal. Ironically, physicians in the 18th century were correct in linking a woman's libido to her ovaries.

Women who have had their

Hysterectomy is major surgery

physicians to understand and empathize with women wanting children. However, these same physicians do not have the same sensitivity when it comes to a woman who is older, that is, over 40, and who prefers to preserve her uterus, and, if indeed a hysterectomy is warranted, to keep her ovaries.

One American gynecologist, Ralph C. Wright, in 1969 justified the increasing number of hysterectomies as follows: "The uterus has but one function: reproduction. After the last planned pregnancy, the uterus becomes a useless, bleeding, symptom-producing, potentially cancer-bearing organ and therefore should be removed." This view continues to be popular today among gynecologists.

We are all afraid of cancer. Ovarian cancer is particularly frightening. Because it is generally

ovaries surgically removed, are routinely prescribed Hormone Replacement Therapy (HRT), the popular medical treatment for menopause. HRT "replaces" the hormones in the woman's body which the ovaries are no longer producing. This is ironic because the justification for removal of the ovaries in first place was because they were no longer needed! Moreover, HRT does not improve a woman's libido. To improve her sexual desire, testosterone (male hormone) is given in addition to HRT. This does increase sexual desire dramatically, but also causes negative side effects such as a deepened voice, increased growth of body hair and a larger clitoris. All this is a constant reminder that something is not quite right.

Up until 1975 rates of hysterectomy were increasing. In recent years, in some but not all parts of

Canada, rates have been marginally declining. In part, I believe this is due to women becoming increasingly knowledgeable about the abuse of this surgical procedure. Research has shown, as in Saskatchewan, that when hospitals are audited, the rate of hysterectomy decreases dramatically.

The most effective way to reduce the number of unnecessary hysterectomies performed is through active consumer participation in choice of treatment and in the development of public policies regulating health care. More public education and research is necessary to support this involvement.

If your physician recommends a hysterectomy for reasons other than cancer or hemorrhaging, your surgery is elective. Once your uterus and/or ovaries are removed there are no replacements. Take your time in deciding. Here are some suggestions:

Education - Understand your choices and know your alternatives; read books and articles; speak to women who have already had a hysterectomy.

A second opinion - Seek out second, third or fourth opinions if necessary. It is okay to be labeled "doctor shopper." A good consumer always shops around before making a purchase.

Counseling - Can be helpful in identifying your feelings and concerns, at the same time supporting you in the decision making process.

A rule of thumb - In deciding whether or not to have a hysterectomy, ask this question: "Is the treatment worse than the condition?"

Unless the reason for a hysterectomy is to preserve life, the most conservative treatment always should be explored first. Hysterectomy is the last alternative and only to be considered when all else fails.

Zelda Abramson is a women's health counselor in private practice in Toronto.

Further Reading

Coping With A Hysterectomy, Susanne Morgan, Dial Press, New

York, 1984 (out of print, but check your local library)

How to Avoid a Hysterectomy, Lynn Payer, Pantheon Books, 1987

Hysterectomy Before and After, Winnifred B. Cutler, Harper and Row, New York, 1988

Hysterectomy: Learning the Facts, Coping with the Feelings, Facing the Future, Wanda Wigfall-Williams, Micheal Kesend Publishers, New York, 1987

No More Hysterectomies, Vicki Hufnagel, Penguin, Markham, 1989

Overcoming Endometriosis - New Help from the Endometriosis Association, Mary Lou Ballweg and the Endometriosis Association, Congdon and Weed, New York, 1987

The Endometriosis Answer Book, Niels H. Lauersen, Fawcett Columbine, 1988

Understanding Menopause, Janine O'Leary Cobb, Key-Porter Books, Toronto, 1989.

Support Services

Winnipeg Women's Health Clinic
419 Graham Ave., 3rd floor
Winnipeg, MB, R3C 0M3
(204) 947-1517

Vancouver Women's Health Collective
#302, 1720 Grant St.
Vancouver, B.C. V5L 2Y7
(604) 255-8285

Women's Health Resource Unit
1402 8th Ave NW
Calgary, AB, T2N 1B9

Ontario Endometriosis Network
P.O. Box 3135
Markham Industrial Park
Markham, ON, L3R 6G5
(416) 968-3717

P.I.D. Society
P.O. Box 33804
Station D
Vancouver, B.C. V6J 4L6
(604) 684-5704

Hysterectomy Educational Resources and Services/HERS Foundation
422 Bryn Mawr Ave.
Bala-Cynwyd, PA 19004
(215) 667-7757



all under one roof

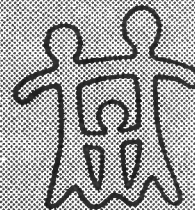
Parentbooks

201 Harbord St. Toronto, Ont. M5S 1H6

Mon. - Sat. 10:30 - 6:00

Phone (416) 537-8334

Childbirth Education for Informed Choice



- small classes
- extensive resource library
- individual instruction available
- creative workshops for siblings - to - be

Sheryl Nestel, B.A. CCE
Certified Childbirth Educator
50 Ellsworth Avenue
Toronto, Ontario M6A 2K3
(416) 658-3135

MY STORY, OUR STORY

Search for an Alternative

Heather Tucker

I look at all the scribbles and notes on my calendar. The lists of details, appointments, phone calls that lead up to today's entry "10 AM SURGERY." I imagine myself lying on the operating table at this very moment and I shiver at the thought. I recall the struggles of the past month that have brought me to this place where with both confidence and uncertainty I can erase this last entry from my calendar and begin again.

Many women will face the threat of a hysterectomy during the most productive and fulfilling years of their lives. This is my journal of the past month, following the course which led me to begin searching for an alternative to a hysterectomy.

Entry 1: I saw Dr. D today. He told me the fibroid, a benign tumor on the wall of my uterus, has grown past the point where it can be left, and I need a hysterectomy. I was too overwhelmed to ask questions. I left with a handful of forms, a booklet explaining hysterectomies and the reassurance that it would be really nice to be rid of this discomfort.

Entry 2: I have read this booklet over and over again. It sounds simple enough, but as I look at the diagrams with their clearly marked incision lines, I imagine this empty space inside of me and it just feels wrong.

Entry 3: A date has been set for my surgery and I have spent most of the day on the phone making arrangements. I never quite realized how much I do. Trying to cover everything is difficult. A rest from all of this is beginning to look attractive! I am amazed at how many people I talked with today who have had a hysterectomy. Or their mother, sister or friend has had one. I was disquieted by some

of the comments they made. "I was so depressed afterwards," "sex is really difficult," "she is a different person," "I am exhausted all the time." The booklet makes it seem simple, but now I am not so sure.

Entry 4: I needed to talk to a medical person that I felt comfortable with. My GP listened, addressed all my concerns and reassured me that this was the best course of treatment for me.

Entry 5: I went to the library. All the books were out except for one. Obviously I am not the only one looking for answers. This book is very helpful; it is current, well researched and documented with the latest studies. The author confirms my feelings that a hysterectomy is anything but simple and routine. It is a serious altering of a woman's body that can have far reaching consequences. It certainly would treat my symptoms effectively but in doing so may leave me with a whole new set of far more serious symptoms to deal with. The only clear advantage I can see is no housework for eight weeks! I learned also that there is an alternative for me, a myomectomy, a procedure which would remove the fibroid and not the uterus or ovaries. A hysterectomy should not be my first approach but my last resort!

Entry 6: I needed to talk with someone to help me sort through all the incongruities between what the doctors are saying, and what I am reading and hearing from other people. It's not easy to find support. I followed a suggestion and called the College Street Women's Centre. I talked to Zelda. She was

well informed, she listened and really seemed to understand my concerns. I'm feeling much clearer in my thinking and surer of the direction I want to take.

Entry 7: I went to see Dr. D again with literally pages of questions, confident that I would be able to negotiate the best treatment for me. I told him that I wanted to keep my uterus and have a myomectomy done. He told me that this was not possible because of the risks of blood loss, adhesions and reoccurrences. Besides, I did not want to have any more children so it was not that important to preserve my uterus. I asked him about the current literature that states the uterus is important for the healthy functioning of my ovaries, cardiovascular system, endocrine system, central nervous system and for sexual response. He simply said that this was not true in his experience and that if the ovaries were retained I would not have any problems.

With my uterus seemingly lost I asked that the cervix be left in place. He asked me why I would want it. I replied with the information I had read that it enhanced sexual func-



Kelley Aitken

tion, lessens the possibility of urinary incontinence, and produces prostaglandins necessary for ovarian function. He said again that this was not true in his experience, and since my cervix was prolapsed and could become infected, even cancerous, it would have to be removed. He reassured me again that everything would be fine.

The more I think about his comment that these things have not been in his experience, the more I see the truth in it. No one other than a hysterectomized woman could truly experience the consequences and many of them are saying there are problems, changes and losses.

Entry 8: I talked with another gynecologist who agrees with everything my doctor has said, and confirms that a hysterectomy is my best option, and that it should be done before it compromises the health of my other organs.

Entry 9: I am sitting in my sun room, a place where I usually feel so content, but right now I feel such grief. I am going to lose a very significant part of myself, a part of me that continues to contribute to my health and well-being and I feel powerless to do anything about it.

Entry 10: I talked with Zelda again. She is more help than she realizes - just to sort through all the input with her helps me clarify things. I also talked with a colleague who had a hysterectomy a year ago. She shared with me very intimately her feeling of loss and grief and just for her honesty I felt reassured that my feeling were normal and valid.

Entry 11: Dr. D called. I guess he sensed my anxiety. He wanted me to postpone surgery and get another opinion. I told him that I already had and that I was resigned to it. Besides, the idea of having to reorganize everything is more than I can handle.

Entry 12: I informed Zelda that I had decided to go ahead with the surgery. She encouraged and supported me, but with great wisdom suggested I call Hysterectomy Educational

Resource Services (HERS).

Entry 13: I watched a TV program on hysterectomies and cried for two hours afterwards. Brian held me and said we wouldn't do anything until we had sorted through everything and felt right about it.

Entry 14: I talked with Nora Coffey at HERS. She said quite simply, "The fibroid can be removed. Find a good fertility specialist to do it. Your uterus is valuable, keep it!" There was really no discussion. These were the facts and I believed them, but now what do I do with them?


Entry 15: Written information arrived from HERS. I have read it over and over again and I am alarmed, no, terrified! Are these things true or are 5,000 women lying? I held Elizabeth for a long while and she cuddled into my shoulder. She drew a wonderful response from deep within me. Could I risk a curtain being drawn on these feelings?

I called Karen and asked her to tell me what sex had really been like since her hysterectomy. She said she never really thought about sex anymore, but when they did have sex it could be okay if she really "worked" at it. How sad it feels to think about working at something that should be spontaneous and fun.

I don't want to just be able to get through my days, but I want to maintain the joy I feel in my relationship with my husband, my children, my work.

Entry 16: Sarah came home from school and asked me what was wrong. I told her I was confused and I didn't know what to do. In her wonderful eight-year-old wisdom she looked me squarely in the eye and said, "You know mommy, you don't have to do anything you don't feel right about doing." And she is absolutely right! I called my GP and made an appointment for tomorrow.

Entry 17: Walking home from the doctor's office I felt foolish and bewildered, but at the same time I felt absolutely wonderful. He had been kind and supportive and took



**TORONTO
WOMEN'S BOOKSTORE**

73 HARBORD STREET
TORONTO, ONTARIO, M5S 1G4
(416) 922-8744 • HOURS:
MON., TUE., SAT. 10:30 TO 6
WED., THURS., FRI. 10:30 TO 9

the responsibility of explaining everything to Dr. D. But I don't think he really understood why trying to find an alternative to a hysterectomy was so important to me. After all, hadn't thousands, perhaps millions of women before me survived it? Yes, this is true, and their symptoms have been treated, but I wonder if their quality of life has really been improved. If there is another option I have to try it first.

Entry 18: Benjamin asked me if he could play with my suitcase. I took out the clothes I had packed for the hospital and told him I wouldn't be needing it for a while. He put in his horses and other treasures and set off on an adventure in the basement. I feel like I am setting off on an adventure of my own, quite unsure of where it will take me, but at least I am starting at the beginning and not the end.

Heather Tucker is a mother and prenatal teacher living in Ajax, Ontario who had a successful myomectomy.

Karen Blackford

A Different Parent

It makes you appreciate your friends, what you have...it shows you that you can't look back...because you can't look at what you could've done...you kind of just look ahead. It makes you live more for right now...what's going on right now in your life.

These are the words of a teenager with a disabled parent in a revolutionary new video produced by the northeastern Ontario branch of Persons United for Self Help (PUSH). *Talking it Out in the Family* teaches viewers in the general public how to improve communication in families by sharing the experiences of parents with disabilities and their families. Although funded through conventional government sources, this video is unique. Until now educational audio-visual resources about parenting have rarely addressed the dynamics associated with disability. *Talking it Out in the Family* portrays real life situations and is enacted by people living the experience. Most original of all is the positive perspective of the video. The script focuses on strengths which arise from dealing with the barriers faced by disabled persons.

As a member of PUSH and the Disabled Women's Network (DAWN), I was aware that a large number of persons with disabilities

were also parents. I knew for example, that child care provisions are as essential as accessible transportation for successful member turnout at meetings. My own chronic illness had influenced relationships within my family. As a researcher in child development studies and an instructor in community health nursing, I also had an academic interest in the dynamics of life with disabled parents.

At a 1987 workshop sponsored by DAWN, mothers expressed their surprise when I led a discussion about parenting. "No one ever seems to even realize that mothers with disabilities exist," commented one participant. "Because we have a disability, everyone assumes that our families look after us. People don't seem to realize that we are carrying out the responsibilities of parenting."

During this workshop I learned about the many faces of parental disability. I heard from a single parent whose leg had been amputated because of cancer. She was concerned about her teenager's adjustment to the prosthesis and to fear of cancer. Another mother with severe arthritis discussed her need for physical adaptation in her home to ensure that she could keep up with a testy two-year-old. This mom described her efforts to supplement the family income through office work. She had to tolerate the opinion of extended family members who felt

that because of her arthritis, she was unwise to ever have had a child. Stories related to chronic illness, to perceptual impairment and to accidents were shared. These parents were facing very large challenges. At the same time, life in these families appeared to be characterized by innovative solutions, open discussions and evident joy in parenthood.

I left the workshop with the impression that mothers and their families would benefit from the opportunity to share information and ideas with each other about adjusting to disability. These were not the "dysfunctional" parents I had been educated to expect. Rather, these mothers were devising solutions that demonstrated creativity and communication skills and were promoting positive family adaptations to disability. When I brought these ideas to a PUSH Northeastern meeting in Sudbury, the group endorsed a proposal to apply for funding in order to produce a video on the subject.

In order to gather preliminary insight for the video, I interviewed parents with various disabilities and their families in Northeastern Ontario during 1988-89. One father with a job-related permanent leg injury stated that he and his family were treated as if they were "no longer part of society." In their northern lumber town, "even the kids were downgraded and pushed



“It was important to me that I could take care of my baby by myself ”

around” because people thought he was being “lazy.” This man’s partner described her difficulty in learning about medication effects or surgical procedures when her husband’s treatment occurred at distant medical centres. The couple related some past incidents of despair and breakdown in communication. However they had managed to talk out their feelings and start again in the face of crisis. Their focus at the time of the interview was similar to that of many other parents. “I just want them to grow healthy, to play with them, to be a real happy family.” Open dialogue with their daughter and with their son who has a hearing impairment was their priority.

A couple from another town were both legally blind. As they raised their toddler, they initiated devices such as bells on the youngster’s shoes and a practice of precise organization within their home. The sugar bowl is always put back where it belongs. Even disasters associated with dirty diapers taken off at inopportune times are well handled. In their small mill town, however, services for blind persons are almost “non-existent.” While “bowling and card games are available in Toronto,” this young mother frequently feels “caged” at

home while her husband is on the road with his work. Neighbours do not mix. Local expectations seem to be for blind persons to be “in a nursing home.”

These interviews and others showed me that parents with disabilities in communities away from large centres were often challenged by neighbours’ ignorance and non-acceptance of disability, by high rates of unemployment, by winter weather and by lack of accessible services. Yet these parents were overcoming the odds and were working with their families to keep communication open and to find solutions.

Originally our plan was to have volunteer actors follow a preset script based on earlier interviews. However, when the director began to work with volunteer parents with disabilities and their families, the real stories of these individuals brought life to the screen. Using themes devised from my interviews as a guide, three families were invited to tell their stories on camera. They were asked to repeat themselves innumerable times so that the editorial committee would have a number of “takes” to choose from. This committee was made up of

PUSH members, all of whom were parents with various disabilities.

As *Talking it Out in the Family* begins, young parents Lillian and Paul describe the surprise they both felt when she first discovered she was pregnant with Andre. Lillian is paraplegic and has been in a wheelchair since her teens. Neither of them had expected that she would be able to conceive a child. “It was the nurse who suggested a pregnancy test. I couldn’t believe it when the nurse announced...that I was pregnant. Then I had to wait six hours to tell Paul. I was dreading telling him.”

“I always know when something’s worrying Lillian. It’s written all over her face,” explained Paul. Lillian went on with the story, “When he asked me “What’s wrong? Are you pregnant?”, I was so relieved!” The couple share their initial worries about her health during pregnancy and about possible health problems in their baby. Only after they were reassured about both were they able to start to get excited about parenthood.

They discuss the need to do problem solving around physical access and baby furniture. Paul and Lillian first devised a carrier which ensured that Lillian could carry her new baby safely and comfortably

Health Wanted

Call for Submissions

Women and AIDS

Les Editions Communiqu'Elles, a Montreal-based feminist publishing house, is now seeking submissions for an anthology to be entitled *Canadian Women and AIDS: Beyond the Statistics*. Scholarly articles, research papers, fiction, poetry, personal testimonies and interviews from HIV-positive women and women with AIDS, their caregivers, relatives and lovers, researchers, social scientists, sex workers and activists will be considered. Deadline for submissions is September 1, 1990.

Contributions may be in English or French and depending upon funding, contributors may be paid. Book launch will be December 1, 1990, to coincide with International AIDS Day, which this year will focus on Women and AIDS. Send submissions to: Jacque Manthorne, Editor, Les Editions Communiqu'Elles, 3585 St. Urbain, Montreal, Quebec, H2X 2N6 or phone (514)844-1761 or fax (514)842-1067.

Menopause

Healthsharing is presently planning a special issue on Menopause for the Spring of 1991. We believe it is important to advocate an alternative to the medical model of menopause as a disease. This issue will give special attention to menopause from a cross-cultural perspective. Some suggested topics for consideration are: Menopause and race, class and culture; hormone replacement therapy; hot flashes; menopause and women with special health problems; alternative therapies; sexuality; lesbian experience of menopause; early menopause.

Article proposals are due ASAP. Please send to *Healthsharing*, 14 Skey Lane, Toronto, ON, M6J 3S4. Deadline for final articles is October 15, 1990. This issue will include a resource section. If you know of or are part of a menopause group, or know of printed or audio or video resources that should be included, please write to us.

from room to room. Eventually Paul adapted a crib by creating a door that swings out instead of up. The door permits Lillian to place her son solidly on his bed without having to stretch down over the crib side. "It was important to me that I could take care of my baby by myself," explains Lillian.

From the beginning both were confident that this mother would be a capable parent. "I always knew she could do it," states Paul. Both Paul and Lillian are vocal about the joy they feel in parenting. "To see him laugh and play and do all the baby things. There's a good feeling that you brought him into the world."

In another segment, we hear from Heather, a teenager whose father has multiple sclerosis. She describes alterations in family schedules and activities related to her parent's disability. "As I got older, it got worse. Then my sister had to drive him to work in the mornings. We started to help him up the stairs." Heather openly explains her feelings. "Some of the normalness was gone. You couldn't do things spontaneously any more. Dad couldn't get ready on time. Sometimes you feel resentful - you want to do something but you just can't do it. Then you realize that you're not losing a lot. You're just changing things for something else." She stresses the importance of discussing feelings with friends. "I'm lucky because I have my older sister to talk to," says Heather, "You have to have friends and someone to talk to."

Cory's mother also has MS. His parents acknowledge the importance of their son's friends. His basketball team members are very significant in his life and are welcome at their home. His father Geoff says, "He worries about his mom, that she might some day need to be in a wheelchair, or in hospital." Cory agrees, "Its pretty scary stuff."

The number of persons with disabilities in Canada who are also parents is difficult to determine. Unfortunately, the *Health and Activity Limitation Survey* carried out by Statistics Canada did not

The number of disabled persons playing an active parenting role is on the increase

establish figures related to parental disability. This lack of statistical recognition exemplifies how parents with disabilities are a marginalized group within Canadian society. All we can learn from Statistics Canada is that 1,817,430 adults between the ages of 15 and 64 reported a disability in 1988.

However, the number of disabled persons living at home and playing an active parenting role is on the increase. As prosthetic devices, medical intervention, accessible housing, transportation and employment become more available, expectations of persons with disabilities for leading a full social life have also increased.

Individual symptoms can differ from one disability to another. The unpredictable course and outcome of chronic illnesses such as multiple sclerosis present unique difficulties for both the "patient" and for family members. An accident or surgery which leads to permanent impairment may be more predictable, but may cause an enormous crisis that can be difficult to adapt to. Families with a disabled parent often experience a change in lifestyle which may include isolation as a result of the "illness/disability" stigma, reduced mobility, reduced financial assets, a change in residence to gain physically-adapted accommodation, a change in the division of labour among family members, increased public scrutiny and support from



formal agencies.

The key to adapting to a crisis such as parental chronic illness appears to be family communication. Families which previously managed through haphazard dialogue and traditional authoritarian forms of decision making, must adapt their approach to discussion in the face of stress or find themselves overwhelmed. Family meetings can be a forum for accomplishing the important tasks of sharing and affirming the feelings and activities of each member, for setting priorities, for planning activities and for sharing decision making. Disappointment and anger can be expressed along with caring and encouragement.

The children of parents with disabilities seem to be adept at role taking, which is the ability to adopt the point of view of the other person and a critical element in building mature relationships with other people. As part of my work in Child Development Studies, I sent questionnaires to 35 early adolescents whose mothers all had either multiple sclerosis, Lupus (a chronic rheumatic disease) or kidney disease. These youngsters demonstrated a high potential for mature friendship relations, particularly in their understanding and appreciation of the concepts of acceptance, humour, character admiration and genuineness. Increased empathy and role taking ability might be a

result of their unique family situation where parenting style is probably more reciprocal and mutual than in other families.

With their peers, children can practise problem solving while making the most of their abilities to understand others. However, discussion groups for children of disabled parents are rare. Funding and leadership are necessary to initiate such groups.

The term disability carries with it the connotation of an inability to care for self and others. Visible signs indicating disability, such as the universal (wheelchair) sign for access, are frequently associated with images of persons being cared for...of persons being carried by...the rest of society.

Society's current view of disability is itself a barrier as high and as overwhelming as any unramped doorway. Negative expectations from others influence a person's performance, reduce self-esteem and can lead to limited goal-setting. All family members can be affected by this pervasive expectation of dependency and lack of competence. Relationships with a person's partner, extended family, child or even child's teacher, may all be modified by preconceived ideas about what a disabled parent can do.

These ideas are based on an attitude termed "abilism." In order to

CRIAW'S *Special Publications on New Reproductive Technologies*

Our Bodies ... Our Babies ... Community Resource Kit

Each kit contains;

- fact sheets on key issues
- information sheets on what you can do about RTs
- A glossary and a list of resources
- Back-up articles
- *Dilemmas*, a publication by the Quebec Council on the Status of Women

Price: \$7.00 + \$1.00 postage

Reproductive Technology and Women: A Research Tool

A bilingual publication which contains a wealth of information for all researchers interested in RTs. This tool contains essays and glossaries in both French and English, extensive bibliographical material and abstracts of key feminist articles and books in English.

Price: \$8.00 + \$1.00 postage

ORDER FORM

_____ Resource Kit(s)
_____ Research Tool
Packages

Send to:

Criaw

151 Slater St.,
Suite 408, Ottawa, Ontario
K1P 5H3

College Street Women's Centre

for Health Education and Counselling

College Street Women's Centre for Health Education and Counselling provides therapeutic and consultative services.

As women and as therapists we are sensitive to the socio-cultural context in which we live. We believe that education is essential to restoring the power and control women need to make informed choices. We are committed to providing an atmosphere where a woman can learn to nurture and strengthen herself.

Services Provided

Individual counselling
Couple counselling
Consultation and education

Groups

Body image
Menopause
Early menopause
Sexual abuse/incest
Guilt, anger and shame

Areas of Specialization

Life transitions
Relationships
Personal growth
Sexual abuse
Sexual assault
Incest
Eating disorders
Body image
Sexuality
Reproductive cycle

- abortion
- PMS
- menopause
- infertility
- pregnancy
- gynecological health

Head injury

Therapists

Zelda Abramson, M.S.W. Nancy Davis, B.F.A., M.A.
Counsellor/Consultant Art Therapist

Patricia McGillcuddy, M.S.W.
Counsellor/Consultant

Karin Jasper, Ph.D. Margaret Powell, B.Sc., OT
Psychotherapist Therapist

We are fee for service. A sliding scale is available.

College Street Women's Centre
for Health Education and Counselling
517 College Street, Suite 410
Toronto, Ont. M6G 4A2
Tel. (416) 929-1816



understand the politics of disability, it may be helpful to consider the parallels between abilism and other forms of oppression such as sexism. Feminists have critically re-examined traditional social theories to determine how these ideas are created and maintained by mainstream male-dominated society. Feminist authors demonstrate how theory reflects the values of our patriarchal society, and the importance of developing theories based on equality.

Societal bias against the disabled means that families of parents with disabilities are often relegated to the general category of "dysfunctional families" even prior to assessment. Caregivers are often advised to evaluate the extent to which a parent's disabling condition has negatively affected other family members. Parents with disabilities are still often designated as the "patient" or "client." Words have great influence. These descriptive terms reduce the power of these parents in the family and in the community.

A political network is on the move to counteract abilism in Canada. Self-help groups have formed under the national umbrella of the Coalition of Provincial Organizations of the Handicapped (COPHO), which is based in Winnipeg. Some of these groups, including PUSH in Ontario and DAWN across Canada, bring together persons with different disabilities. They raise public awareness and work toward political change at national and international levels to improve the quality of life for people with disabilities. Hopefully, with the support of this network, more researchers will be open to the perspective of persons with disabilities.

The stories in this article capture a number of the recurring themes which ran through all my interviews. There is a great focus on communication in these families. Parents talk openly with each other and with their children. Flexibility in scheduling or arrangements and ingenuity in problem solving enable these families to organize their lives. These parents radiate the pleasure they

feel in being part of their children's lives. Parents and children care for each other and are concerned about the future. They describe their dreams for a better world, which they hope their children will see.

In the video, one parent probably echoes the wishes of all disabled parents when she concludes, "I hope he'll grow up with the attitude that having a disabled mom is a positive experience...that people can be different but still alright."

Karen Blackford is a researcher and advocate for the rights of persons with disabilities, sole support mothers and low income tenants. She is currently completing a doctorate in sociology at York University.

Author's note: In this article I offer no apology for approaching these families with an agenda to identify strengths. Just as feminist theorists acknowledge that feminist science must be biased because sexist science is biased, so this visual exploration of family life is weighted openly to counteract much of the otherwise negative portrayal of parents with disabilities.

The author is grateful to the three families who agreed to tell their story for the video, to the Northeastern Branch of PUSH for submitting the original proposal and to the video project committee: Randy Beland, Yvette Beland, Cathy Cuthbertson, Karin Hoffman, Jerry Main and Dolly Ruddy. Laurie McGauly directed, Gary Michalak evaluated and Brian Hart filmed the video. Funding was obtained from Health Promotion Branch, Health and Welfare Canada and the Office for Disabled Persons. The author is solely responsible for the views expressed in this article. These views do not necessarily reflect policy of Health and Welfare Canada, the Office for Disabled Persons or Persons United for Self Help.

Talking it Out in the Family can be purchased at cost price from PUSH Northeastern. Contact Randy Beland, PUSH Video Project, RR#3, Site 7, Box 11, Sudbury, ON, P3E 4N1. The video comes with a free information guide for families, self-help groups and caregivers.

HEALTHWATCH

Further Reading

The Disabled Women's Network Canada (DAWN) recently published four position papers on women with disabilities; 1. *Who Do We Think We Are: Self-Image and Women With Disabilities*, 2. *Beating the Odds: Violence and Women With Disabilities*, 3. *The Only Parent in the Neighbourhood: Mothering and Women With Disabilities* and 4. *Different Therefore Unequal? Disabled Women and Employment Equity*. \$5.50 each or \$20 for the set (includes postage). Women with a disability who are unable to afford the suggested cost may send whatever they can. Include payment with order to DAWN Canada, 10401 Finlayson Drive, Richmond, BC, V6K 1W8.

Disabled Women's Organizations

DAWN BC

1762 Bayview Street
Surrey, BC V4A 2Z4
(604) 536-4578

Saskatchewan Disabled Women's Network

112-514 Victoria Ave East
Regina, SK S4N 0P9

Consulting Committee on the Status of Women with Disabilities

924-294 Portage Ave
Winnipeg, MB R3C 0B9
(204) 947-2742

DAWN Toronto,

4 Warner Ave
Toronto, ON M4A 1Z3
(416) 755-6060

Action des femmes handicapées de Montréal

7785 Louis-Herbert
Montréal, PQ H2E 2Y1
(514) 725-4123

Collectif femme et handicapée

675 Kerovac, Apt. 11
Québec, PQ G0R 2V3

DAWN-PEI

PEI Council of the Disabled
P.O.Box 2128
Charlottetown, PE C1A 7N7

Women For Change

P.O.Box 1174, Station C
St. John's, NF
(709) 753-5825

PATIENT'S RIGHTS An Agenda for the Nineties

Maggie Burston

Environmental problems, the aging of the general population, new epidemics and inadequate preventive health care all demand that we look critically at our health care system. A process of disenchantment with the medical establishment has set in. While we are aware of the achievements of 20th century medicine - its immense array of sophisticated technology, the life-saving techniques of emergency medicine, surgery and chemotherapy - we also know that in emphasizing these aspects of medicine, other needs have been neglected.

Modern medicine, by focusing on measures for drastic intervention is not teaching us how to avoid getting sick. There is a shocking lack of research into a finer understanding of how human health can best be maintained. And there is an undue emphasis on medical therapies which frequently harm as much as they heal. In fact a bizarre situation exists where some medical therapies promote disease. The overuse of antibiotics is well documented and known to precipitate yeast infections which

are becoming more common. Other research indicates that certain tranquilizers can initiate permanent central nervous system damage; and many studies reveal that the overuse of valium can cause, not cure, depression.

These insights into the damaging effects of prescription drugs acquire a disturbing significance when we realize the extent to which these drugs are used in the general population. Combine this level of drug-induced disease with the growing incidence of Epstein-Barr virus, diabetes, breast cancer and the many instances of unnecessary surgery, and the reasons for disillusionment with many medical practices becomes clear. The stage is set for the growing patients' rights movement.

The issue of patients' rights has emerged as one of the most important for the 1990s. It is not coincidental that defining these rights is on the agenda of groups throughout the country, including the Consumers Association of Canada, the Patients' Rights Association, AIDS information centres and ex-psychiatric patient support groups. Nor is it surprising to find patients' rights on the agenda of ethics committees of universities, physicians' associations and the Royal College of Physicians and Surgeons of Canada.

What is the premise of those working for patients' rights? Our premise is that each of us has the right to information and knowledge which enables us to live a disease-free life for as long as possible. Our present medical system does not facilitate this educational process. In fact, it is not even seen as partic-



Kelley Aithen

Patient's Rights Resources

Many health activist organizations (such as AIDS groups, ex-psychiatric advocacy groups, etc.) have a patient's rights committee. In Ontario, the Patients' Rights Association has prepared a manual which is currently being revised since new legislation regarding patient's rights is under debate. For more information, contact the Patients' Rights Association, Apartment 315, 40 Homewood Avenue, Toronto, Ontario, M4Y 2K2, (416) 923-9629.

Maggie Burston has established a new non-profit organization, Patient Information Services on Chronic Immune Dysfunction to provide health consumers with information on an individualized basis. A number of nationally and internationally recognized medical experts are on the advisory panel. For more information, contact Patient Information Services on Chronic Immune Dysfunction, 41 Green Valley Court, Kleinburg, Ontario, L0J 1C0, (416) 832-5340.

ularly desirable. Most often, the 'patient' is viewed as incompetent and medical information is considered too complex and specialized.

The right to this educative process has been paid for in blood, pain and tears. The history of women's health care over the past years is convincing evidence. Deaths from Pelvic Inflammatory Disease and infertility caused by IUDs, the addictions to tranquilizers, the depression and immune breakdown caused by birth control pills, recurring yeast infections and the increasing number of unnecessary hysterectomies - all these have taught us that we must understand everything affecting our bodies and our minds.

To achieve a more comprehensive understanding of our health care there are a number of basic things that people need. To understand what is happening to us we

need access to information on:

- the validity and accuracy of both mainstream medical testing and alternative methods of diagnosis
- the purpose and potential for success of every treatment undertaken
- the possible side-effects of drugs both in the short and long-term
- alternative health care, in particular information on homeopathy, naturopathy and acupuncture

In addition to this information, basic relationships within the health care system must change as well. The paternalistic nature of the doctor/patient relationship is central to maintaining an arrogant omnipotent doctor and a passive "my doctor will fix it" patient. As we demand a more active role in our health care, doctors are starting to change by stressing patient involvement as opposed to compliance. Health professionals must examine and incorporate the principles of preventive health care. As they access this approach, doctors will realize that the success of alternative therapies, those of diet, nutrition, allergy control and relaxation techniques, depend on the health educated patient. And the informed patient will realize that this education empowers them to participate in an equal working relationship with their doctors.

We need doctors who combine therapies, who are prepared to be honest about the shortcomings of their recommended tests and treatments, who realize that the patient's participation in medical decisions is a primary factor in their treatment and who encourage their patients attempts at self-responsibility by granting access to all records. Most importantly, we need doctors who are prepared to engage their patients in a serious investigation. We want doctors who, when faced with a complicated history of symptoms, do not assume that we are malingering or neurotic, but help us search for deeper reasons such as immune malfunction or environmental stress. No more of this, "Go home and live with it," or, "Why don't you see a psychiatrist?" or, "You're over the hill." But instead an inquiry into

whether the patient is getting all that she needs — an inquiry that is conducted within a framework of mutual respect.

These new approaches reflect the philosophy that people can improve their health by changing the conditions of their life. But this change, no matter how small is possible only for those who understand the relationship between how they live and how they feel. This insight is usually acquired as the result of a learning process - a process that cannot take place in the limited time allotted for consultation between a doctor and her patient.

So, how can we get our health needs met? The key lies in public health education. The priorities and funding of our health care system must be reorganized. Patients and doctors must lobby for the development of a national network of patient information centres. These centres could provide information geared to a specific need in an accessible format. They could sponsor courses of general study on preventive health, reproductive health, diet and nutrition. They could provide specially trained patient information counselors and all of this can be done in the languages of the local community that the centre serves. While harnessing the information from medical data banks, these centres could access the wealth of research presently available. Audio tapes, videos and computer programs could instruct in an easy and enjoyable manner on all health-related subjects.

These steps could dramatically change our health care system. Medical costs will be reduced as patients need to visit their doctors less frequently. And the pains and uncertainties of sickness will be alleviated by the support of a more informed and involved community. Health education would be available to all, not just those who can afford it.

Maggie Burston is the founder of the Candida Research and Information Foundation in Canada, and has been a patient information advocate for many years.

The National Eating Disorder Information Centre presents:

Making Connections:

Early Childhood Trauma, Addictions & Eating Disorders

A conference exploring the intersecting dimensions of early childhood traumas, addictions and disordered eating behaviours...

Topics Include:

- The Relationship between Early Childhood Traumas & Disordered Eating Patterns
- Working with Adult Survivors of Abuse in Eating Disorder Treatment Settings
- Body Shame
- Immigrant Mothers & Daughters
- Eating Disorders & Addictions
- Working with Food & Weight Issues in Abuse & Addictions Treatment Settings
- The Emotional Abuse of Fat Women
- Self-Harm & Eating Disorders
- Deprivation, Violation & Early Childhood Trauma

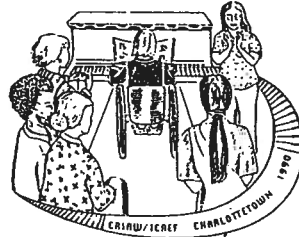
Featuring:

- Susan Wooley, Ph.D., Co-Director, Eating Disorders Clinic, Associate Professor of Psychology, University of Cincinnati
- Bonnie Burstow, Ph.D., Feminist Therapist, Faculty Member, Carleton University, Co-Editor, *Shrink Resistant: The Struggle Against Psychiatry in Canada*
- Karin Jasper, Ph.D., Psychotherapist, Founding Member, Herize: A Weight Prejudice Action Group, Author, *Are You Too Fat Ginny?*
- Catrina Brown, M.S.W. (In progress), Feminist Therapist, Author, *Getting Beyond Weight*

...And other well-known theorists & clinicians

Date: October 24 to 26, 1990
Cost: \$150.00 - Bursaries & Travel Subsidies also available
For more information contact: CW1-328, 200 Elizabeth Street, Toronto, Ontario, M5G 2C4, (416) 340-4188

"The more we get together..."



14th Annual CRIAW Conference
November 16-18, 1990
Charlottetown, PEI

Keynote speakers:

Joan Meister, Past President of DAWN Canada
Monique Begin, former Federal Cabinet Minister

Presentations: papers, panels, workshops, media

Themes: Women and Health Care
Disability Defined
Action Research
Women on the Margins
Feminist Instruction
Mothers and Children
Faces of Feminism...and much more

For information contact:

Muriel Houston or Estelle Reddin
PO Box 2271
Charlottetown, PEI
C1A 8B9 or call Anne Mazer (902) 368-4510



Canadian Magazine Publishers Association

CANADIAN MAGAZINES

FOR EVERYBODY

Now, 230 publications to choose from!

The new 1990 Canadian Magazine Publishers Association catalogue is the one source that describes 230 of the latest and best Canadian magazines.

There's an incredibly wide variety of topics, points of view and special interests.

They're all yours to choose from when you get our current catalogue with its easy-to-use detachable order form.

Fill in the attached coupon today and for just \$3 (to cover postage and handling), we'll send you our new catalogue.

Please send me the new 1990 CMPA catalogue. I enclose my cheque for \$3 to cover postage and handling.

NAME _____

ADDRESS _____

CITY _____

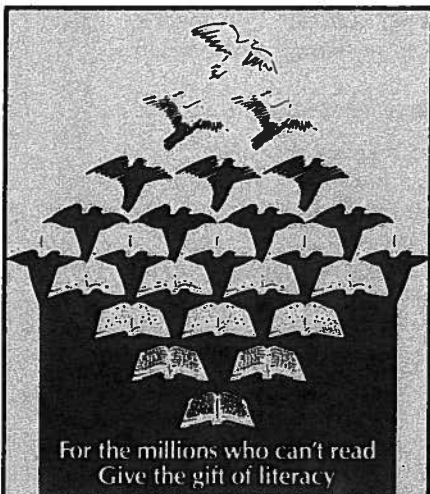
PROV. _____

POSTAL CODE _____



2 STEWART STREET
TORONTO, CANADA
M5V 1H6

HG



For the millions who can't read
Give the gift of literacy

1990 is International Year of Literacy. Five million Canadians cannot read or write well enough to function in today's society. Every Canadian has a fundamental right to the freedom that literacy gives. You can help. Become a literacy volunteer. Write to your member of parliament. Read, and read to your children.

For more information, or to make a donation, contact:

Canadian Give the Gift of Literacy Foundation
24 Ryerson Avenue
Toronto, Ont. M5T 2P3
(416) 595-9967

Canadian Give the Gift of Literacy is a project of the book and periodical industry of Canada.

RESOURCES & EVENTS

No Choice

No Choice is a five minute documentary film that deals with the complex issue of abortion and how it relates to women living in poverty. Produced as part of the Five Feminist Minutes Program of NFB Studio D, it is available for rental and purchase from: Canadian Filmmakers Distribution Centre, 67A Portland St., Toronto, ON, M5V 2M9 or phone (416)593-1808.

Ontario Endometriosis Network

The Ontario Endometriosis Network, formerly a Canadian branch of the US based Endometriosis Association, is a newly formed resource group for women with endometriosis. They will be coming out with a quarterly newsletter beginning in September 1990. For more information: The Ontario Endometriosis Network, P.O. Box 3135, Markham Industrial Park, Markham, ON, L3R 6G5 or (416) 968-3717. Membership is \$10 a year.

Infertility Awareness

Infertility Awareness is a newsletter published six times a year by the Infertility Self-Help Support Group which also offers counseling, referral and support to individuals with infertility concerns, and education and assistance to associated professionals. The Nov./Dec. 1989 issue focused on endometriosis with six articles on that topic. Available from Infertility Awareness, 180 Metcalfe Ottawa, ON, K2P 2B8.

Women Organizing Against Violence

Match International Centre has produced a resource kit containing a collection of materials examining

the global dimension of violence, international statistics on violence, women's personal accounts, a printed and audio-visual resource list and more.

Women Organizing Against Violence is available for \$15 per copy. (Cost includes postage and handling. Discount for orders over 10. Third World Women's groups free. All orders must be prepaid.) Order from Match International Centre, 1102-200 Elgin, Ottawa, ON, K2P 1L5.

Reproductive Technologies and Prevention

The Infertility Dilemma: Reproductive Technologies and Prevention is a 31-page document prepared for the Canadian Advisory Council on the Status of Women. Written for the non-medical reader, it focuses on the need to address the more global issues of infertility and reproductive health promotion rather than concentrating on costly reproductive technologies.

Available free of charge from CACSW, 110 O'Connor Street, 9th floor, Ottawa, ON, K1P 5R5 (613) 992-4975.

New Reproductive Technologies

The Ontario Advisory Council on Women's Issues has developed a workshop kit to help groups and individuals explore the complexities of new reproductive technologies (NRTs) and to prepare presentations to the recently formed Royal Commission on Reproductive Technologies. There are three parts to this workshop. Part One is an exercise to help individuals assess their own personal beliefs on many aspects of NRTs. Part Two assists participants to develop an analytical approach to specific aspects of

NRTs. Part Three provides some ideas for action.

Available free of charge from the Ontario Advisory Council On Women's Issues, 880 Bay Street, 5th floor, Toronto, ON, M7A 1N3 (416) 326-1840 or fax:(416) 326-1836.

Ask Me No Questions

The Public Legal Information Association of Newfoundland (PLAIN), which provides information on law in plain language to the public and to teachers and students in particular, has just published a novel for young adults about sexual abuse, with a companion teaching guide. *Ask Me No Questions* is a story written to educate young people on the nature of sexual abuse and to engage them in informed discussions on this pressing issue. Legal options are also discussed.

Ask Me No Questions is available for \$5.95 from local bookstores or Prentice-Hall Canada Inc., 1870 Birchmount Road, Scarborough, ON, M1P 2J7. The Teaching Guide is available for \$4.00 from PLAIN, P.O.Box 1064, Station C, St. John's, NF, A1C 5M5 or from Prentice-Hall.

The Sanitary Protection Scandal

The Women's Environmental Network has published a book as part of their campaign against chlorine bleaching of soft tissue paper products — sanitary napkins, tampons and disposable diapers. Bleaching gives a whiter-than-white look, but the process releases dangerous dioxins and other organic chemicals. *The Sanitary Protection Scandal* investigates the implications, both for the environment and human health and concludes with a number of action guidelines, an extensive reference section, a glossary and appendices including the names and addresses of manufacturers.

The Sanitary Protection Scandal (Aldgate Press, London, 1989, 140 pp) is available in bookstores or by sending a money order for £6.40 to Women's Environmental Network, 287 City Road, London, EC1V 1LA.