

M.E. The Invisible Disability

"I have to rest after

walking a quarter

of a block, it is just

too much."

Ingrid Deringer

Myalgic Encephalomyelitis (ME), also referred to as Chronic Fatigue Syndrome (CFS), Epstein Barr Virus (EBV) amongst a host of other names, is not a new disease. Evidence of its existence dates back to 1869.

Regardless of its long history, ME is not a well known disease. One of the reasons may be because it has been known by close to a hundred different names throughout its history. It has only been in the last ten years that researchers and doctors have begun to realize that these various diseases are one in the same.

Another reason ME is not well known is because it is not easily recognizable. By and large the medical community has not taught doctors to recognize the symp-

toms and the nature of the disease. As well, there is no one single test that can determine if one has ME or not. Diagnosis at this stage is done by evaluating symptoms and eliminating other possible causes.

The symptoms stressed as *primary* symptoms vary depending on which country you are in. In Canada, Dr. Byron Hyde, the leading researcher on ME, defines ME as "a chronic illness of at least six months duration that develops after an acute infectious disease in a well, physi-

cally active person. In this disease the person develops an unusual form of muscle failure experiencing fatigue, pain or exhaustion in the exercised muscle". So for Hyde, muscle failure is the primary symptom. Other countries stress the fatigue as the primary symptom.

For a better understanding of what muscle failure means, I will quote myself (a sufferer for eight years) and others I have listened to and interviewed over the last 3 years: "I feel like my body has been run over by a truck", "I don't have the strength to brush my teeth", "I have to rest after walking a quarter of a block, it is just too much", "it hurts to be hugged". This profound exhaustion, weakness, and pain is one of the reasons those of us with ME don't like the term *Chronic Fatigue Syndrome* or the stress on fatigue as the primary symptom. It is obvious from the quotes that we are not "just tired all the time" it is a much deeper exhaustion and weakness that is often accompanied with pain. The word *fatigue* just doesn't describe the experience.

The list of symptoms is long and varied. Other symptoms, besides the muscle failure, include reoccurring sore throats, headaches, chest pains, poor short term memory, poor concentration, blurred vision, sensitivities to cold, inflamed lymph nodes, numbness, hypersensitivities to foods, toxins, perfume, and smoke. The list of symptoms goes on and on. Not all people experience all

these symptoms nor do they experience any one symptom all the time.

ME is really a systemic disease that affects all parts of your body. The symptoms come and go, sometimes even in the same day. Some symptoms are more debilitating for some people than others. For example, cognitive problems, such as memory and concentration are so severe in some people that they struggle with everyday living. Many find it impossible at times to read, watch TV., hold a conversation, work, drive or go grocery shopping. For others, the muscle pain and weakness is so severe that they are literally bedridden, yet some are affected only mildly or sporadically and are able to continue to work, but in a more limited way.

Many times, as is the case with other chronic illnesses, people will experience depression. There are several reasons for

this. One reason may be that people find it difficult to accept the changes in their abilities. It seems that most people who acquire a chronic illness go through a process where they mourn their lost health similar to mourning for a lost loved one. To some people it means they have to give up their jobs, their sports, and even the ability to go for a walk around the block.

Another reason for depression is that many people find that no one believes they are ill. It is common for people and especially for women not to be

believed by doctors, friends or family when they become sick. The symptoms, because they are sporadic and rarely visible, can seem to others to be imaginary or signs of a neurotic. It can be very depressing to find that you have no support from anyone.

In a society where medical doctors are viewed as the continued on page 3



raphic: Alexa Berton

authority on our bodies, getting their seal of support is particularly important. However, people with ME, and women in particular, have a difficult time getting support and understanding from doctors. This is not surprising since women historically have not been taken seriously by the medical establishment. Women with ME often report that they are given tranquilizers or antidepressants by their family doctors and dismissed. They are often told they are "menopausal", "imagining", or "hypochondriacs". Women have been seen and continue to be seen as neurotic, complainers, and liars by the medical establishment. For example, I was told by a specialist that I couldn't possibly have anything wrong with me because there was no such disease where you suddenly felt bad one day and not the other. His understanding of chronic illness was obviously limited. Unfortunately, I went home thinking I had really gone insane.

Coping day to day can be difficult for both women and men. But for women, there seems to be a unique problem that is, asking for and getting help. We, as women are more often than not, the caregivers of others. To suddenly be on the receiving end is a difficult transition to make. Women are generally not used to asking for help and others are not used to providing it. We are used to being *depended on* not *being* dependent. Many women with ME report there is a real need to learn how to be dependent and to feel okay about it.

The attitude about ME seem to be changing especially in B.C. where the media have picked up on it and where groups such as MEBC and MECANADA have emerged. Now there are numerous support groups across Canada and an especially strong network in B.C. Here women and men can go to get the most up to date information, talk to others about what they are experiencing, have their experiences validated and hear how others cope. Thanks to these groups and groups like these, ME is beginning to be more widely recognized by the medical community and the society at large.

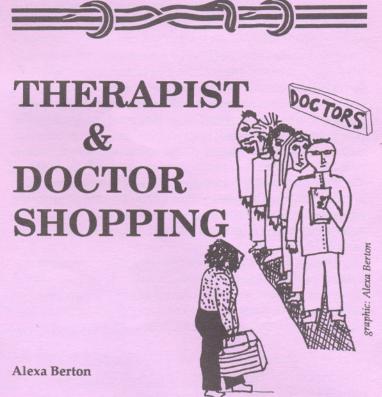
In the support groups you hear about literally hundreds of different treatments people have tried to cure or alleviate symptoms. I have heard people report all sorts of treatments and remedies. Some try the medical route such as small doses of antidepressants, pain killers, tranquilizers, and sleeping pills, etc. Some try the homeopathic route or naturopathic route. Others try herbs, mega vitamins, and algae. Others go to psychic healers and hypnotherapists, and try mediation, visualization, relaxation, and yoga. Some find relief from massage therapists and chiropractors. Still others, find relief in strict diets. Most people try combinations of the above or all of the above. To date there is no one treatment that has made ME go away for all people.

In my experience as a researcher on women's experiences of ME, as a sufferer, and as a frequent member of support groups for three years, I cannot say that one treatment is better than another. For every horror story I hear there seems to be a success story. (By "success" I mean that it has helped to alleviate the symptoms somewhat.)

Most people with ME are very sensitive to drugs of any kind and find that tranquilizers, antidepressants, sleeping pills, and muscle relaxants often do more harm than good.

A large percentage of people with chronic illnesses live at or below the poverty line.

The good news is that ME does not get worse over time. Although you rarely hear about it going away completely, you do often hear about people feeling better and better over time. If you have ME or know someone who has it, the Vancouver Women's Health Information Centre has information on ME and phone numbers of ME support groups.



Women often call us looking for that magical list of good, reliable, progressive, feminist practitioners in this ever growing city. I'm beginning to wonder if maybe such a list really does exist as so many women come to us in search of it. I know we don't have it. Part of the reason we don't have it is philosophical. We believe that women have been told what's right and wrong, good and bad about their health and health care for too long. We have a system that allows women to make their own decisions based on other women's experiences.

We have a doctor file and we have a therapist file. Each is divided and cross referenced by geographical location and specialty.

In the doctor cardfile, female and male general practitioners (GPs) are listed separately and by geographical location, while specialists are only listed by specialty. In the actual file, there are other patients' response questionnaires on these practitioners. From these you can try to decide if there is a particular practitioner you might like to see.

The therapist cardfile is set up a little differently. We send therapists a questionnaire about the work they do and from that, we cross reference them in categories related to the

an important omission from page 3, fits in at the bottom of column one...

That is not to say that medical science may not come up with a cure one day, but to date, very few people seem to react well to medication of any kind.

Some treatments such as relaxation, meditation, and visualization are safe unless people take them to the extremes. Some approaches (i.e. Louise Hay) have the underlying assumption that people are responsible for their ill health, and all they have to do is change their attitude and they will be well. When they fail to get well, people feel they are paying for some past life mistake. But meditation, visualisation, and relaxation, still seem to be some of the best ways to deal with the daily stress and pain of ME, according to most ME sufferers.

One successful treatment for me has been to change my diet. Other people have found this does not work. After eight years of being ill, I have found that eliminating dairy, wheat, eggs, coffee, tea, alcohol, oats, barley, rye, pork, any fatty meats, and an assortment of other foods (some other people also include sugar, and all meats) has enabled me to alleviate the most debilitating symptoms. Some people however, find it very difficult to keep on a strict diet because they are not well enough to cook and shop for nutritious foods and/or they cannot afford them.

Naturopathic remedies seem to be good for some people and not for others. The problem for many is that it is, like the restricted diet, an expensive route to take, and for the majority of people with ME, it is simply not accessible.

kind of subjects they work with and processes they use. So when you look through the therapist's file, you'll find both this questionnaire and client response questionnaires to help you in your decision making.

Feelings about practitioners are very subjective. This is our other reason for not recommending a magic list (outside of certain legal problems we might encounter through recommendation). Some practitioners are wonderful for some people while those same ones are not acceptable to others.

In this issue of The Women's Health Rag, we are including one doctor questionnaire and one therapist questionnaire for you to fill out. These forms are anonymous (don't put your name on it) in hopes that you will feel comfortable sharing your experiences without censorship. We have found that some women feel badly about commenting on their doctors and therapists. They often say he/she did something unacceptable but that he/she is a nice person and they wouldn't want to negatively affect their practice. There is space to include the positive and the negative information on the questionnaire. It is important that we as women begin speaking about the unacceptable things that are done to us by the nice people in our lives. Doctors who are nice people can make mistakes (intentionally and unintentionally), it's important to let others know so that they can avoid the unpleasant results of a doctor's mistakes either by being aware of the doctor's history when seeing them, or by avoiding the doctor altogether. We also accept good reports! If you have had good experiences with your practitioner, write those down too.

Please help us update our files by filling out the questionnaire included here and sending it to us. Don't think we don't accept questionnaires from places other than Vancouver, women often ask us if we know of prationers in Surrey, Delta, Langley, etc., please send them in. Thank you!







Nicole Hollander/"My weight is always

ACCESSINGNS ACCESSINGNS ACCESSINGNS OUR OPTIONS?

Valda Dohlen

Every year, thousands of women in B.C. face the problem of an unplanned pregnancy, and each of these women faces the decision to either carry that pregnancy to full term or to have an abortion. While the individual circumstances which shape that decision vary, - age, socio-economic background, ableness, or marital status - many of these women choose to have an abortion. Their decision to terminate a pregnancy is not always an easy one, nor it is always one a woman experiences as a 'free choice'. It is however, a decision that only she can make, as it is only she who knows her financial, emotional and physical state of being that so intimately shapes the conditions of mothering.

As with any other health issue, women seeking an abortion need information about their options. And like other decisions regarding their health, they often turn to the medical system for assistance and support. Far too often, however, their efforts to get this information are met with delays, refusals and even blatant harassment. As a prochoice organization, the Vancouver Women's Health Information Centre is committed to providing women with the information that is all too often difficult to get, and in this article we want to share information on what the present status of abortion services is in B.C.

At present, a woman who chooses to terminate an unwanted pregnancy in British Columbia has two choices. She may refer herself to one of the two free-standing clinics in the province, both of which are located in Vancouver, or she may seek a hospital abortion through a referral to a gynecologist. There are several factors which shape this decision, including whether or not she has medical coverage, what stage in the pregnancy she is at, her financial situation, the availability of abortions in her commmunity and her general health.

Free Standing Clinics

There are two non-profit free-standing clinics in B.C.: The Everywoman's Health Centre which opened in East Vancouver in 1988, and the Elizabeth Bagshaw Women's Clinic which opened in Vancouver's downtown area in 1991. Both facilities provide abortions by vacuum aspiration under local anaesthetic in a supportive and non-judgemental atmoshpere.

As free-standing clinics, neither facility receives government funding, and women are charged a fee for abortion services. Fees vary depending on whether a woman has B.C. medical coverage and at what stage in the pregnancy she is seeking a termination. It is important to note that no woman will be turned away from the Everywoman's Health Centre for financial reasons, and women who are unable to pay the full fee on the day of the abortion, have the option of arranging a payment plan, which allows them to make affordable monthly payments. The following are the fee schedules as of March, 1992

Everywoman's Health Centre

With MSP	Without	MSP
\$200.00	\$300.00	

7 to 11 weeks \$200.00 \$300.00 12 to 13 weeks \$225.00 \$325.00

Elizabeth Bagshaw Women's Clinic With MSP Without MSP

7 to 11 weeks \$225.00 \$335.00 12 to 13 weeks \$275.00 \$385.00 14 weeks \$300.00 \$410.00

Both clinics operate on a self-referral basis, so women aged 19 years or older can make an appointment by calling the clinics directly. Women ages 16 to 18 can refer themselves, however at the Everywomans's Health centre they must also have either the consent of one parent or the written opinion of two physicians, which can be obtained by doctors at the clinic. For young women under the age of 16, parental consent is mandatory in Canada. If parental consent is not

possible, girls 15 and under may go through a clinic in Washington state where there is no age legislation.

During her time at a clinic, each woman will receive pre-abortion counselling services, designed to give her comprehensive information about the procedure and the risks involved. Women are welcome to ask questions and

are free to discuss any issues of concern to them with their support counsellor. In addition to pre-abortion counselling, both clinics offer a full range of reproductive health services, including non-coercive decision making counselling, post-abortion counselling, birth control counselling, birth control prescriptions, post-abortion follow up care and STD screening and treatment.

At both clinics, a woman is welcome to have a friend, partner or family member with her during the abortion and recovery. Women are also accompanied by a clinic support counsellor during the abortion. In general, every effort is made to provide women with quality health care in a supportive atmosphere designed to ensure her physical and emotional well-being.

Hospital Abortions

There are generally two reasons why women seek abortions in a hospital rather than a clinic. First, clinic

abortions are only available to the 14th week of pregnancy, while hospital abortions are legal in Canada to the end of the 19th week. Second, for women with MSP health coverage, hospital abortions are free.

While the advantages of going through the hospital are no fee and later terminations, the disadvantages include inadequate support counselling services, a long wait - typically three to four weeks - and numerous appointments, including a visit to a general practitioner for a referral, an initial office visit to the gynaecologist, and then a third visit to the hospital for the abortion. Moreover, because the majority of hospital abortions are performed under general anaesthetic, during which women are put to sleep, there are additional risks to the procedure and a longer recovery period.

Outside the Lower Mainland

Fearing harassment from anti-

choice forces, many doctors in

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With two local abortion clinics and several hospitals providing abortion services, women who live in the Vancouver area have more options than women outside of the lower manland. For women in the interior, even access to hospital abortions is limited. Few hospitals allow doctors to perform abortions in their facilities, and finding out which ones do can be difficult. Fearing harassment from anti-choice forces, many doctors in small communities keep the whole issue of access clouded in secrecy. Even women's support services in the community refuse to freely give out information on who is performing abortions, and far too often a woman will only learn of her local options if she is lucky enough to find a

sympathetic doctor who will refer her to the right specialist. Even with this help, many women still choose to travel considerable distances for a clinic abortion because hospital abortions in small communities can be extremely difficult to arrange with confidentiallity.

Looking to the Future

With the recent election of an NDP government, activists in the B.C. abortion rights movement are optimistic that limited access to government funded abortion services will soon be a thing of the past. Although talks of provincial funding are in progress, no formal announcements to fund the two existing clinics in the province have been made. Until such funding is provided and until facilities are expanded province-wide, access to abortion services will remain problematic, particularly for low-income women in B.C.

To help fill the void in abortion support services, the Vancouver Women's Health Information Centre presently provides women with fee, non-coercive decison-making counselling. We also have information on which doctors are presently providing abortions in B.C. and where they are practising. If you or someone you know is facing an unplanned pregnancy and want more information, please contact us

New Books of Note

Kate McCandless

The Black Women's Health Book: Speaking for Ourselves

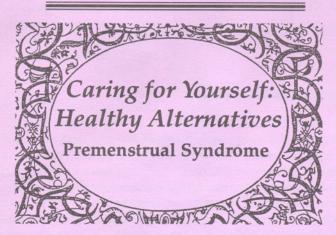
Edited by Evelyn C. White, (Seal Press) 1990, 290 pp.

Kecia Brown gives this book a rave review (in a Fall 1991 Healthsharing reprint from Sojourner: The Women's Forum). A collection of articles, essays, personal stories, and narratives by health care workers, covering a wide range of topics on Black women's health. "Not only does it speak on health, it speaks to the heart; it is a fine piece of literature for the soul. The experiences it contains speak to all of humanity."

Angels of Power: and other Reproductive Creations

Edited by Susan Hawthorne and Renate Klein, (Spinifix Press) 1991, 271 pp.

To deal with the alarming and often confusing array of new reproductive technologies and the debate surrounding them, we need not only facts and analysis, but imagination and creative freedom. This Australian feminist press offers us an anthology of fiction, poetry and drama envisioning future possibilities and responding creatively to the questions raised by new reproductive technologies.



Helen Idler & Alexa Berton

For some women, menstrual cycle changes can be an exciting time in which creative energies seem more abundant and emotions feel more freeflowing and passionate. Yet for other women whose cyclical changes are uncomfortable, depressing, and even debilitating, menstruation is not something they look forward to.

Premenstrual Syndrome, or PMS, is a syndrome which affects many women. It occurs 1-2 weeks before the onset

of menstruation, around the time when estrogen levels drop and progesterone levels increase. An imbalance in these hormones is generally thought to be the main cause of PMS, but the exact cause or causes have yet to be found.

Symptoms of PMS are as varied and numerous as the women who experience them. They include any or all of the following: acne, depression, headache, backache, feeling out of control, sore breasts, general nervousness, changes in mood or personality, insomnia, fatigue, dizziness, joint pain, and bloating due to water retention.

Some factors which may contribute to PMS are: food allergies, coming off the pill, poor diet, high stress, hypoglycemia, candidiasis, and hypothyroidism.

In the medical establishment, PMS is usually considered an illness and as such is treated with hormones, antidepressants, and an assortment of other drugs. Unfortunately, these drugs do not affect the causes of PMS, requiring ongoing use to deal with symptoms.

Medicalizing this natural female process disempowers women and encourages them to slip into passive acceptance

of therapies in which they are essentially guinea pigs. It convinces them that they are sick and need drugs to get better instead of teaching them how to strengthen and balance their bodies so that they feel more in control of their bodies and less overwhelmed by their cycles.

Prior to going the drug route, try out some other methods that have fewer negative side effects. Work towards getting your body and mind into a state of good general health. The keys to maintaining this are good nutrition, exercise and stress reduction. By good nutrition we mean



motherwart

eating fresh vegetables and fruits, whole grains, fish, legumes, and seeds, and drinking plenty of water to help eliminate toxins. It is important to cut down on certain foods to keep PMS at bay. These foods are salt, caffiene, red meat, dairy products (particularly cheeses because they have a high salt content), sugar, and processed or junk food (also high in salt). Animal products are good to avoid not only because they usually have a high salt content, but they are laced with hormones that the animals were given, which might have a negative effect on your own hormonal balance). Experiment with your diet. Toward the middle of the month, reduce your intake of these foods, then next month, if you can bear it, try cutting them out altogether. Many women also find it helpful to eat smaller, more frequent meals.

Another thing to consider is cutting down on or altogether quitting smoking cigarettes and/or marijuana Marijuana especially has a direct and negative effect on reproductive organs.

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Exercise and stress reduction go hand in hand. Exercise reduces stress, increases circulation, and can, potentially enhance one's general sense of well-being. Swimming, walking, cycling, yoga and aerobics are all good ways to get excercise, but there are many other ways to incorporate exercise into your life. Do whatever you find enjoyable and try do it regularly.

Although exercise will usually help to alleviate stress, some people prefer yoga, guided imagery, relaxation tapes, or meditation to fully relax. Self-help support groups can play an important role for women who feel isolated and overwhelmed by PMS. Getting encouragement and support from women who have had similar experiences is empowering and can reduce emotional stress considerably.

There are various effective alternatives to standard medical treatments for PMS. Not all of these will work for every woman, just as not all drug options work for everyone. Still, some women find relief through acupuncture or massage. Others take vitamin supplements and/or herbal remedies. Although vitamins and supplements can be effective, the costs can be prohibitive for some women. Supplements most often used to treat PMS are: calcium with magnesium chloride, evening Primrose Oil (or a less expensive substitute of flaxseed oil with borage), B complex, B6, B5, vitamin E, a multivitamin, vitamin C and vitamin D.

Herbs, are a less expensive way to reduce the effects of PMS. Drinking teas made from single herbs or a combination of herbs is a simple way to improve the way you feel. Some women have found the following herbs to be effective: dong quai, raspberry leaves, false unicorn, squaw vine, blue dohosh, sarsparilla, kelp, blessed thistle, wild yam, and motherwart. It is important that the herbs be of high quality (not old!) and that you take them regularly. Sporadic use of herbal teas, though a pleasant ritual, won't be medicinally effective. Herbs also come in more concentrated forms known as tinctures, which are sold in health food or vitamin stores. They come in various combinations to help alleviate symptoms of PMS. Experiment with these and with loose teas to find which ones help you, but do be cautious as herbs are potent medicines. Read up on them carefully before you take them and never take more than the prescribed amount, especially with tinctures. More isn't necessarily better! If you have questions or concerns that aren't answered through reading, consult an herbalist.

For more detailed information on herbs, vitamins and diet for PMS, see:

Self-Help for Premenstrual Syndrome, by Michelle Harrison, M.D.,

Pain-Free Periods, by Stella Weller

PMS: A Self-Help Approach, by the Vancouver Women's

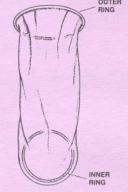


News Flashes

Reality?

Female condoms, according to a recent Vancouver Sun article, have sold out swiftly to curious Swiss: 25,000 packs of three, at seven dollars each pack, were eagerly snapped up.

Will women in other countries follow suit? And if they do, will such popularity continue, or will it prove to be a case of "tried it once and didn't like it?" despite its being touted



Reality Intravaginal Pouch (TM)

as "effective" and "empowering".

The pouch shaped device is seven inches long, with a lubricated polyurethane membrane nearly twice the thickness of a male condom. A flexible ring fits inside the vagina like a diaphragm, anchoring the sheath behind the pubic bone. A second ring sits outside the body. The vagina and labia are entirely lined thus providing more protection against infection than either the diaphragm or the male condom. Does it affect women's sensation? We'll have to wait for the results of the tests, the popular articles don't discuss this. Will the costs go down so that women can afford them?

Although the Reality (TM) Intravaginal Pouch has been approved for sale in Canada, it won't be available until later



Reality (TM) pouch in place

on this year. The targeted market is the large number of actively dating single women concerned about protection against AIDS. Will they accept or snub this rather cumbersome and costly product as just one more phase of latex reality?

PMS/Prozac Study

The psychiatry department of Shaughnessey Hospital has been recruiting women to be part of a cross-Canada study of PMS treatment using an anti-depressant drug, Prozac, also known as Fluoxetine. Participants in the eight month study are divided into three groups, two taking Prozac at different doses, and a third taking a placebo. Women considering such treatment should be aware that Prozac is a potent drug and has been surrounded by controversy. Common side effects are anxiety, nervousness, insomnia, drowsiness, fatigue, tremors, sweating, dizziness or lightheadedness, anorexia, nausea, and diarrhea. Factors which may make the use of Prozac dangerous are: individual hypersnsitivity to the drug, pregnancy or breastfeeding, interactions with other drugs and physicial conditions such as diabetes or liver disease.

People on Prozac have been known to become uncharacteristically aggressive and violent either to others or to themselves.

The symptoms of PMS can be devastating, but the question is, are they devastating enough to trade them for the dangerous effects of Prozac?

Tax Break!

In December 1991, the Everywoman's Health Centre won a victory in court and ended a long battle with Revenue Canada by gaining a charitable tax number. Tax deductible receipts have now been issued for donations received from 1988 to date. The clinic wishes to thank all donors, past and present, as their generosity ensures that women who cannot afford a clinic abortion are not turned away.

Educational Evenings

Spend an evening per month with us learning about women's health issues. From 7:00 - 9:00 pm, the following women will speak:

Thursday, April 9: Carol Ann Letty, practicing midwife will speak on midwifery; what it is, how it's different, and the politics of it. Videos and personal experiences included.

Thursday, May 7: Chanchal Cabrera, practicing herbalist will speak on herbology as it relates to PMS, menopause, fibroids, and other health issues.

Thursday, June 11: Ingrid Deringer will speak about living with ME (myalgic encephalomyelitis).



The Vancouver Women's Health Information Centre Newsletter is a quarterly publication offering information about women's health issues and the projects of the Centre (the Vancouver



Women's Health Collective). We welcome letters, ideas, and requests from our readers. Write to us at:

The Women's Health Rag #302-1720 Grant St., Vancouver, BC V5N 2Y7

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