BEING POSITIVE:
WOMEN LIVING WITH HIV AND AIDS
IN BRITISH COLUMBIA

By

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ABSTRACT

The following study is a phenomenological inquiry into five white, middle class women's experiences living with HIV and AIDS in British Columbia. The purpose, rather than describing AIDS as a medical phenomenon, is to document how being diagnosed HIV positive has affected the women's lives, health, relationships and livelihoods. A context for the women's stories is provided through a critical review of the biomedical model, as well as biomedical and community organizing perspectives on women and AIDS. Mostly verbatim accounts drawn from taped interviews conducted with the five women describe their lives with HIV and AIDS. Experiences surrounding their diagnosis, sources of information about their illness, strategies for coping, management of health, and management of personal and social identities are the themes explored. The women's participation, the role of the researcher, and the work produced are considered parts of an interactive process, demonstrating shared authority between the researcher and participants in the ethnographic process. Documentation of the women's experiences leads to a discussion of the ways in which they successfully manage and control their own health care and well being within the context of larger social forces of sexism, medical bias and stigma. The women are given the last word in the study. In conclusion, a review of their situations three years after their initial interviews contributes a significant emotional and descriptive time-depth to the study.
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DEDICATION

FOR

C.
It is my hope that the following study will be read as a celebration of the five women who participated in its making. Fundamental to this view is the recognition that they are ordinary women. Ordinary in the sense that none hold credit to great appointment or public acclaim. The glimpses into their life stories offered here provide various views of essentially middle class, white, urban, female realities -- impacted by HIV.

None of these women assume any pretense to be a heroine. None have been immune to the burdens of stigma, isolation, fear, and suffering added to their lives with HIV. You may, however, note a lack of explicit anguish in what they have to say. This is a deliberate omission by the women themselves. Perhaps too private, the worst of their suffering is not a portion of the different experiences they have chosen to share.

With courage and generosity they have spoken out in order that others might better understand the difficulties confronting women diagnosed with HIV. They are anxious not to be perceived as victims. They wish to inspire, not sympathy, but constructive practical support from communities and government, which to date have done little to recognize their plight. Perhaps, most importantly, through this document the women seek a means of offering hope, support, and positive possibilities for women newly diagnosed who must confront their own struggle, and find meaningful ways to carry on.

Due to the nature of the disease and the complex diversity of women themselves, there can be no predictable script for women with HIV or AIDS. These stories constitute a brief, but significant, contribution to a much needed literature.

It has been both an honor and a privilege to work with Allison, Lynne, Laura, Heather, and Julie. Any weakness in this text can be attributed to myself.
INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS), was first recognized by the medical community in North America as a distinct disease category just over a decade ago. Understood in biomedical terms as a disease induced by a virus (Human Immune Deficiency Virus, or HIV), AIDS should be seen as presenting an equal threat to all humans. A significant feature of the representation of AIDS as a disease in North America is, however, its association with certain categories of people. AIDS is still depicted as essentially a man's disease, affecting homosexual, bisexual and intravenous drug using males. But women also die from AIDS. Although this topic has received attention only in the last few years, women have been counted among AIDS cases since early on in reporting of the disease (Mays & Cochran 1988:949). The impact of HIV and AIDS on their bodies and their lives, however, is rarely considered. So far the trend in medical studies and literature is to treat women as a "special interest" topic, mainly focusing on their potential role as conduit for the disease through prostitution or childbirth. While increasing concern over the heterosexual spread of AIDS has prompted some investigation, women's own experiences with the disease are consistently overlooked. How women themselves perceive and define their illness, how they inform themselves, what treatment choices they make, what their coping strategies are, how they manage their relationships, how they live and how they die are all topics that have yet to be sufficiently understood or documented. Critically informed studies, particularly ones that take the perspective of those living with HIV and AIDS, are urgently needed to locate women - the otherwise missing persons - in the AIDS epidemic.

The following study is a phenomenological inquiry into five women's experiences living with HIV and AIDS in British Columbia. Its purpose is not to focus on AIDS as a medical phenomenon, but to reveal women's experience of being diagnosed HIV positive:
how it has affected their lives, their health, their relationships and their livelihoods. In Chapter One a context for the women's stories is provided through a critical review of the biomedical model, and the current study is situated in comparison to biomedical and community organizing perspectives on women and AIDS. In Chapter Two, the women's perspectives on their diagnoses, sources of information about HIV and AIDS, management of health, management of identity, and strategies for coping are documented and explored. What they have to say appears in their own words, as verbatim excerpts from the interviews. The women's participation, the role of the researcher, and the work produced are considered parts of an interactive process, demonstrating shared authority between the researcher and participants in the ethnographic process. Chapter Three offers a discussion of the ways in which the women successfully manage and control their own health care and well being and contrasts this with a discussion of larger social forces of sexism, medical bias and stigma that impinge upon their lives. The concluding chapter provides further insight into the women's lives by updating their situations two and a half to three years after their first interview.
CHAPTER ONE
Why Women and AIDS?

The lack of reference materials on women and AIDS was a primary motivating factor for this research. Very few medical studies have been conducted specifically on women and AIDS, and, similarly, relatively few academic references exist on the topic. Of the articles that do exist, most originate from the disciplines of science, medicine, and public health. While it is generally acknowledged that AIDS involves both biomedical and social concerns, social science perspectives on the subject are significantly underrepresented. A small, but growing, selection of works, however, has recently become available, written by women with HIV and AIDS themselves outside academia. Often these texts are grassroots inspired anthologies including brief selections documenting a variety of women's experiences. Both kinds of writing, biomedical and grassroots inspired, represent important aspects of the overall picture of women and AIDS. It is the imbalance of volume, credibility, and coverage between them that is most significant in reflecting society's emphasis and response to women living with HIV and AIDS.

AIDS, including its biological and medical aspects, is fundamentally a social phenomenon involving people in social and cultural contexts. Confronting the disease and its consequences requires a range of theoretical approaches extending beyond the limits of biomedical concerns. In particular, anthropology and sociology have much to offer, including ethnographic descriptions of women's experiences, and models for reflexive and critical investigations of medicine and medical practice.

I will introduce the notion of the biomedical model as a basis for critically assessing much of the existing writing on women and AIDS. After a brief look at biomedical approaches, I will also consider some of the community inspired works
published in the last few years. These two general categories of writing will be presented as contrasting, if not conflicting, perspectives on women and HIV with the latter developing in part as an antidote to the former. In summary to this discussion, I will situate the present study in terms of the two previous categories of literature described.

The Biomedical Model

A theoretical perspective can be simply understood as a set of assumptions that lend shape, focus, and definition to an abstract representation of events. A perspective indicates what constitutes data, patterns for collecting it, and means for its interpretation. Directed by a distinct perspective, modern western medicine is based upon a set of cultural assumptions known as the biomedical model.

Dependent upon the concepts and methods of biological sciences, the biomedical model is characterized by four main assumptions 1) the definition of disease as deviation from normal biological functioning 2) the doctrine of specific etiology - the notion that the explanation of illness is more complete if its description has moved through several stages from symptom, to syndrome, to identification of specific disease - 3) the universality of disease taxonomy, where each disease is believed to have distinguishing features, observable across different cultures and historical periods, and 4) the scientific neutrality of medicine, including the notion of medicine as objective science independent from society (Mishler et al. 1981:1-19). Illness, from this perspective, is viewed as an autonomous entity, defined by universal criteria and isolated from the lives and experiences of patients and physicians (Mishler et al. 1981:2).

Acquired Immune Deficiency Syndrome has only recently achieved status as a distinct category of western biomedical thought. Its definition has been constructed in terms of the four main assumptions of the biomedical model.

Attention was first drawn to the illness as a result of an outbreak of unusual health problems among a small group of otherwise healthy young men in Los Angeles and San
Francisco. Evidence of deviation from normal biological functioning was sufficient to involve the US Centers for Disease Control (CDC), marking the beginning of an officially recognized illness category. Clusters of symptoms were correlated, leading to the identification of a syndrome and, in 1983, the discovery of the human immunodeficiency virus (HIV). Discovery of the virus provided researchers with evidence of a specific causative agent. The legitimization of AIDS as a medical problem was made complete with the formal adoption of the label "Acquired Immune Deficiency Syndrome" to represent the disease. Standardization of the AIDS definition in Europe and America lead to the recognition of the disease in countries around the world, as well as retroactive discovery of HIV in frozen blood and tissue samples from as far back as 1956 (Shilts 1988; Ross 1991).

Science and technology, credited for current descriptions and understandings of the disease, are foci for both funding and hope for an eventual cure. There is an established belief, supported by science and medicine, that AIDS can eventually be conquered through advances gained through laboratories and clinics. Although bioscientific understanding of the disease has progressed at a rapid pace, optimism about the possibility of discovering a cure in the very near future has waned (Maddox 1993:13). Lack of a scientific "magic bullet" cure has shifted emphasis to preventive measures as a means of controlling the spread of AIDS. The social rather than the scientific contexts of AIDS are increasingly recognized as a priority for understanding (Walters 1988: 239). Epidemiology is the branch of medicine specifically geared to investigate the spread, prevention and control of disease in groups or communities (Glanze 1985: 263). It is also the source for most of the information about risk practices, transmission routes and

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1 That HIV is the virus that causes AIDS is currently being challenged by a small, but growing, number of researchers. In the United States 20 people have been documented who have AIDS but not HIV. A full 45% of persons with AIDS in the U.S. have never been tested for HIV, so it cannot be said with confidence that anybody who has AIDS is also HIV positive (Ross 1991).
methods of risk reduction which, from a biomedical perspective, are considered to be the social aspects of AIDS.

Biomedical Perspectives on Women with HIV/AIDS

Epidemiological studies provide most of the statistical information available on women and AIDS. The large majority of these studies are conducted in the United States. American statistics on AIDS, including those specific to women, are not representative of the Canadian situation due to social and political influences, such as demography and health insurance, that are unique to that country. For example, in the US the primary mode of transmission of HIV to women is through intravenous drug use, whereas in Canada it is heterosexual sex (Hankins et al 1988: 11; Health and Welfare Canada 1990:11)

Canadian statistics reveal that the number of female AIDS cases has grown steadily over the last decade. Although this number is smaller than that of male AIDS cases, it is anticipated that the relative rate of new female and male cases will even out in the 1990's (Health and Welfare Canada 1990: 3). Women and AIDS: A Challenge for Canada in the Nineties, (1990) a framework for AIDS education produced by National Health and Welfare Canada cites the following breakdown in female AIDS cases in Canada (all statistics are as of October 1990): 227 female cases have been reported nationally, 139 of those have died; 59% of female AIDS cases are in Quebec, with another 22% in Ontario, 7% in B.C., 5% in Alberta and 7% in all other provinces and territories. About 60% of the female cases for whom this information is available are Caucasian, with the remainder from a range of other backgrounds. About one-third are between the ages of 15 and 29 years, one-third are between 30 and 39 years, and one third are 40 years or older (p. 3).

Interpretation of these statistics can be misleading. The percentages shown are not normalized in relation to population totals for the provinces. For example one might assume from the percentages quoted that Ontario has a higher rate of female AIDS cases than B.C. Actually, B.C. has a higher rate than Ontario despite lower actual numbers.
AIDS statistics tell only part of the story. It is worth clarifying the difference between HIV and AIDS. AIDS is the latter stage of HIV infection. To be HIV positive, or antibody positive, does not mean that you have AIDS. When someone is infected with HIV, antibodies are produced in the bloodstream. These are the antibodies revealed by an HIV test. AIDS is the result as HIV attacks the immune system over a period of time. As the immune system weakens, opportunistic infections, that is infections that already live in the body but which are otherwise controlled by a healthy immune system, may take over (Positive Women's Project (Victoria) 1992: 16). HIV progresses to AIDS when one or a number of the thirty-nine, CDC identified conditions recognized as "life threatening" combine with HIV (O'Sullivan and Thomson 1992: 190). Many people with HIV are "asymptomatic", they feel fine and do not have any health problems. They may fluctuate between ill-health and well-being over a long period of time (Positive Women (Victoria): 16). It is estimated on average that there is an 10.6 to 13 year lag between HIV infection and the onset of full-blown AIDS (Hankins 1990: 6). Projections estimate that approximately 30,000 Canadians of both sexes are infected with HIV. At this time, however, there is no means of accurately measuring the number of HIV cases (Health and Welfare Canada 1990:3).

An indication of the impact of HIV on women can be gathered from studies of perinatal transmission. It is possible for a pregnant woman to pass on HIV to her infant either before or during childbirth. Although perinatal transmission only occurs in only one out of three cases, all babies born of an HIV positive mother carry HIV antibodies in their blood at birth. It takes up to eighteen months after birth to determine if a child is actually infected, or if her status is only the result of antibodies which will eventually disappear (Health and Welfare Canada 1990: 4).

Large population-based studies in several provinces reveal the rate of HIV infection in childbearing women. The highest rates have been documented in Quebec, where one woman in 1,638 who delivered a live infant in 1989 was infected with HIV.
(Hankins 1990: 7). The rate in metropolitan Montreal was one woman in 616 (Health and Welfare Canada 1990: 4)\(^3\). Comparable rates in Ontario for a nine month period ending in June 1990 are one in 3,195 (Hankins et al 1990). The rate in metropolitan Toronto was one woman in 1,976, and in Ottawa-Carleton was one woman in 899 (Health and Welfare Canada 1990: 4). Among pregnant women in British Columbia in 1989, there was one pregnant woman in 3,704 who was HIV-positive (Schechter 1990). The rate in Vancouver and Victoria was one women in 1,300 (Health and Welfare Canada 1990: 4)\(^4\).

Seroprevalence studies give evidence of the magnitude of the HIV problem among women in Canada. They do not, however, provide information about risk factors or the characteristics or the needs of women who are infected. The primary mode of transmission of HIV to women in Canada is unprotected sexual contact, either vaginal or anal, with an infected person. Sixty percent of reported female cases are attributed to heterosexual contact. The second most important means of transmission is injection drug use with needles which have been contaminated by HIV when they are loaned or borrowed. Only six percent of female AIDS cases are attributed to injection drug use. Twenty-five percent of women have been infected through blood transfusions (Health and

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\(^3\) The high rates of infection in women in Quebec may be related to slightly higher numbers than in the rest of Canada of reported cases of AIDS among women who are IV drug users, and significantly higher numbers of women who are of Haitian origin (Hankins et al 1988:11). The Quebec study (quoted in the main text) also revealed a clear association between socio-economic status and HIV infection among women, with residential areas on the Island of Montreal with median revenues below the provincial median accounting for 71 percent of the infections (Hankins 1990:7).

\(^4\) A different perspective on Canadian statistics can be gained by comparison with numbers from the US. A study conducted in November 1987 indicates that New York City shows a higher rate than any Canadian city to date, with one women in 61 being infected (Campbell 1990:409). The same study shows that the figure is even higher for the Bronx where one women in 53 is infected. More recent data (July 1988) reveals a staggering figure of one in 22 women infected in some parts of the Bronx, Brooklyn and Manhattan (Santee 1988:13). San Francisco, one of the earliest cities recognized in the AIDS epidemic, on the other hand has a lower rate of infection among women giving birth, one in 777, than Montreal (Health and Welfare Canada 1990:4).
Welfare Canada 1990: 4)\textsuperscript{5}. No clear risk factor is indicated for the remaining nine percent of women (Health and Welfare Canada 1990: 5).

Biomedically founded, epidemiological studies on women and AIDS are clinically oriented in the sense that they are usually based upon information gathered from a medical or hospital context. Understanding of women is limited to a clinical setting and their physical symptoms. They tend to be perceived primarily in terms of their potential for transmitting the disease. The term "women" appears to fulfill a mainly biomedical definition by suggesting a physiological category distinct from males and associated with the functions of pregnancy and childbirth. Those living with HIV and AIDS need the knowledge and information that science and epidemiology can give them. Much is still to be learned, however, about how HIV infection manifests itself in women. The social, cultural, and institutional contexts of their illness, from their perspective, how they experience HIV and AIDS in the majority of their lives outside of the doctor's office, are not properly taken into account in biomedical understanding of AIDS as a disease.

Community Organization Perspectives on Women and HIV/AIDS

Since the late nineteen eighties there has been a modest, but expanding literature written by HIV positive women and the community group organizers who work to provide services for them. This specific subset of literature on women and AIDS is characterized by multiple authorship and usually takes the form of thematically organized chapters featuring a variety of different women's perspectives. Authors for the texts are either drawn from the membership of a local HIV positive women's group or are put together from submissions solicited by the editors from HIV positive women nationally or even internationally. Two examples drawing from local organizations are *Women, AIDS*.

\textsuperscript{5} This mode of transmission is considered eliminated since November 1985 when the Canadian Red Cross instituted special treatment precautions for blood products (Spurgeon 1988:92). Future statistics should reveal a decreasing trend in this category.

While statistical information is often included in such volumes, the emphasis of the writings is to highlight women with HIV and AIDS speaking out in their own voices about their experiences. A variety of expressive mediums may be represented, for example Rudd and Taylor's volume includes photos, poetry and drawings, in addition to written passages. In contrast to biomedical writings, these texts are highly emotive, filled with pain, anger, sorrow, understanding and celebration. The volumes are produced from a feminist/activist standpoint. Explicit avoidance of a medical or academic context is undoubtedly one of the fundamental goals of such writing. Their purpose is to directly address what is otherwise overlooked or left out of establishment writings about women and AIDS and to do so in a way that is the most accessible to those concerned.

Due to the nature of their compilation, these texts tend not to follow any overtly expressed theoretical framework. Despite the valuable descriptive and anecdotal information included, they are generally dismissed by the formal discipline of academia since they are not produced within the strictures of their domain. The purpose of this study is to provide a means of bridging the gap between these two bodies of literature by bringing women's voices within a social science framework. I do not see this process as one that attempts to "legitimize" what women have to say in any way. Authority naturally resides in their experience. My wish is to contextualize, through conventions acceptable to academia, information and experience largely undocumented and unexamined in that
realm. The challenge has been to provide a meaningful, critical analysis that will prove the anthropological enterprise legitimate in representing the cause of those marginalized, without perpetuating the trivialization of their concerns and the balance of power against their favor.

Critical Medical Anthropology, Phenomenology and Ethnography

Critical medical anthropology's perspective on illness considers the social, cultural, and institutional contexts of patients' experiences, as well as medical practice, to be topics of interest and study (Mishler et al. 1981:1). In these terms, AIDS is understood as a social as well as a biological fact. Social, rather than biophysical, constructions of AIDS as a disease are the primary consideration of this work, with individual ethnographic representations of five women's illness experiences providing the primary foci of interest. Fundamental to the study is a phenomenological approach to collecting and representing the women's stories. This approach pays close attention to experience as it is lived, prior to any second-order determinations. The aspect of phenomenology used in the present work is what Kestenbaum refers to as "non-philosophical phenomenology", that is an exploration of experience, consciousness meaning and subjectivity (Kestenbaum 1982:27). Verbatim transcripts from the women who volunteered to participate provide the basis and direction for the study. Although a critical perspective is taken as the overall framework, the participant's commentary on their experiences lend the main power and emphasis to any critical perspective the study has to offer. The women's self-directed choices in dealing with their illness, in themselves, offer significant critique to medical approaches to the treatment of HIV and AIDS. The study engages several issues currently debated in medical anthropology, such as the importance of the role of the researcher, the need for adequate connections between micro and macro-level analyses and the problem of merging theory and praxis (Singer 1990; Scheper-Hughes 1990; Frankenberg 1988; Richters 1988; Bibeau 1988). As researcher/author, I have made a
conscious effort not to remove myself from the ethnographic representation provided. An explicit accounting of myself in the work is intended to create a more direct connection between the active fieldwork phase of the study and its formal written presentation. The notion of ethnographic authority is engaged throughout the overall interactive process of this study, specifically in the editing phase where each contributor reviewed sections relevant to her interviews as they were written up. The balance of authority between myself as researcher/author and the women participants is, I believe, successfully maintained by a written format that does not shy away from lengthy interview excerpts.

HIV and AIDS present significant challenges to science, medicine and especially to health care. As perhaps has not been so evident in the past, in the case of illnesses that have been successfully "controlled" through conventional medical means, AIDS draws attention to the limitations of the biomedical approach to illness. This study begins at the boundaries of medicine. It begins where medicine has no jurisdiction to provide a blueprint for survival for the women who's stories you are about to read. Through this document they provide their own models for living with HIV and AIDS.

Locating Women with HIV in B.C.

Although the British Columbia Sexually Transmitted Disease (STD) Control Program estimates that there may be over 500 women infected with HIV in the province (as of March 26, 1990), 29 cases of women with AIDS have been officially recorded (as of September 30, 1992) (B.C. CDC 1992: 4). The small number of documented cases and their random isolation by geography contribute generally to the lack of profile of women as a group. Not surprisingly there are few organizations or service groups specifically catering to women's needs. Even those women who have access to existing services, not all are interested in joining an organized support group. Some women may prefer private counseling, others no contact at all with AIDS organizations. Personal preference, fear of negative consequences - losing a job, friends, an apartment - or the wish to protect a
spouse, family, or children may keep a woman from disclosing her HIV status. In some cases, individuals may not even confide in their own family. Finally, it is quite probable that a woman diagnosed HIV positive may not know, or even have heard, about another woman in the same circumstance. This situation creates a context of solitude and uncertainty for the women involved. And presents a challenge to the researcher.

Voluntary access to women with HIV and AIDS, and the ability to ensure adequate means of confidentiality were the two main problems I confronted in recruitment.

Women for this study were purposely not recruited through hospitals, City Health Department, Ministry of Health, or Ministry of Social Services and Housing administrative channels. Although any of these avenues could have provided a roster of identifiable subjects, in all cases I perceived undesirable contingencies related to potential control or subject coercion.

To gain access to patients through a hospital or agency I would have had to gain approval from and associate my study with, either a hospital administration or the City or Provincial Health Departments. Working through a hospital would entail conforming to administrative directives and rendering my study open to their review. The notion of being introduced to HIV patients through the health care team responsible for their well-being struck me as potentially coercive. Access to women through a social service agency seemed to suggest a similar compromise and potential for coercion. In addition, social service access might tend to reinforce existing stereotypical categories of persons with AIDS such as intravenous drug users, sex trade workers and street youth, while overlooking those less susceptible to government intervention. Women able to afford private consultation and medical care are not targeted by social service agencies and are able to protect their identities.

My goal was to be as much as possible a peer to the participants in the study. I wanted to avoid being a member of an establishment influential to their lives as HIV
positive women. I also wanted my work to be as free as possible from the bias of organizations I might otherwise wish to assess or criticize. How to contact women in such a way that their participation would be voluntary was my primary concern.

Fieldwork

I began my fieldwork by volunteering to participate in the B.C. Task Force on AIDS: Women and Children. The B.C. Task Force is an informal group of interested and concerned parties that meet bi-monthly in Vancouver to exchange information about women, families, and AIDS. Operating as a resource organization, rather than a support group, the group has no funding, no official mandate or membership, and no formal hierarchy. It is constantly inspired by the energy of its founding member, Kathleen Smith, who is also responsible for organizing the practicalities of minutes, mailouts, and meeting arrangements.

Begun modestly in 1987, the group has grown to include over forty participants. Represented are a broad array of health care professionals, social workers, street nurses, educators, councilors, volunteers, persons with AIDS (PWA's), as well as representatives from the B.C. Coalition For The Disabled, the Hemophilia Clinic, Greater Vancouver Mental Health, AIDS Vancouver, and the Vancouver PWA Coalition. Members bring to the meetings information, videos, books, and handouts from their respective associations, or from conference and international conventions they have attended.

With its diverse membership and assorted political perspectives, the Task Force provided me with a unique opportunity for meeting others active in dealing with issues surrounding women and AIDS. At every meeting I was able to introduce myself and my study, and to make contact with the volunteer organizations offering support services specifically for women living with HIV and AIDS.

To recruit women for my study, I chose to target non-medical and non-government AIDS support organizations whose membership is voluntary.
Volunteer Response

I submitted an advertisement (see Appendix 1) calling for female volunteers to AIDS Vancouver, AIDS Vancouver Island, the Vancouver Persons With AIDS Coalition, as well as The B.C. Task Force on AIDS: Women and Children. Care was taken in writing the advertisement to outline the terms for ensuring the participant’s anonymity and confidentiality. I received special permission through the University Ethics Board for volunteers to sign the required consent form (see Appendix 2) with their initials only.

It is difficult, however, to introduce oneself adequately through a brief advertisement. It is also almost impossible to inspire the confidence and trust required for the intimate and often painful disclosures about living with HIV. I had hoped to attract ten volunteers from a variety of socio-economic backgrounds. As a result of my recruitment procedure, I had to accept that my sample would be biased towards those aware of their status, those in contact with the groups targeted, those responsive to the terms of the advertisement, and those willing to participate.

Five women responded to the advertisement and volunteered for this study. As it turned out, the women fell within a predominantly middle-class economic category with gross incomes ranging between $20,000 to $70,000. All had been aware of their status for at least two years (range between 2 and five years), had achieved a sense of personal acceptance with their diagnoses, and none were, at that time, in a state of medical crisis.

The manner in which the women responded is, I believe, significant. It revealed that, below the surface of public reserve and secrecy, and in the absence of formal organization, women living with HIV are forming communication networks, life-lines of information and support, among themselves.

My advertisement for the study was posted. I was actively involved with the B.C. Task Force and the Women's Network, lobbying for the urgency of documenting women's experiences living with HIV. Of course, included in this work was the promotion of my
own project and the search for potential volunteers. For three months I received no response. No volunteers.

I realize now that I had been undergoing a necessary trial period. I was being watched and assessed by those around me. All those I came in contact with at the Task Force and the Women's Network agreed with the importance of HIV positive women's voices being heard. It was myself as a person-- my sincerity, my values, my role as a researcher, my social background, and my sexual politics -- rather than the purpose of my study, that were being assessed.

I was aware that in the eyes of some people I did not always make a good impression. I found all organizing around AIDS highly politicized. It seemed I found more acceptance among the establishment-oriented workers, such as social-workers, hospital staff, city and federal government workers than I did among the more grass-roots organizers. This had less to do with my convictions than with my being a white, middle-class, heterosexual, university student. It is possible there were those who chose not to participate in the study because they could not empathize with me as a person.

The first person to approach me, disclose her status, and express her interest in participating in the study, was Allison. Allison was well-known to me as a co-member of The B.C. Task Force. We had spoken together regularly at meetings and even taken the bus home together. The Task Force had sponsored me to attend the annual AIDS Conference held by the University of British Columbia in November 1989. I saw Allison there and we sat together for some of the presentations.

During one of the morning coffee breaks Allison drew me aside from the crowd of delegates into a quiet hallway. She told me that she was interested in my study, that she agreed with the importance of HIV women speaking out for themselves, rather than being represented by others. She asked me if, as of yet, any women had come forward. I said no. Then she told me she would like to volunteer: that she was HIV positive.
It was a powerful moment for both of us. I was very moved by her disclosure. I was also surprised because I had known her for so long without truly knowing her situation, and concerned because I knew her to be pregnant. I had many questions to ask. Allison explained to me her concerns about confidentiality. We agreed not to further our conversation that day, but rather I would contact her at home and we would make arrangements for an interview. Then Allison told me that there was someone else: someone she had heard about through the PWA society and had spoken to on the telephone. This other young woman also happened to be attending the conference that day. Allison said she had mentioned my study to her and that she might be willing to speak with me. In mentioning this other person to me, Allison was careful not to reveal her name. I did not know the woman's identity until she later made herself known to me.

The chairperson of the Task Force had arranged that those interested in the topic of women and AIDS were invited to meet over an informal lunch. About eight women showed up, including Allison and myself. Lynne was one of the other women there.

Meeting me in this select, but public, grouping gave Lynne an opportunity to size me up in a safe, relatively anonymous setting. We each introduced ourselves around the table, stating our name, affiliations, and our interests. Lynne spoke out last, introducing herself merely as an HIV positive woman. At the conclusion of our luncheon meeting, Lynne passed me her telephone number on a piece of paper and told me I could call her.

Over the next two months I met the other three volunteers in a similar manner, through an introduction via another participant in the study. Allison played a key role in making my work known to others with whom I would have otherwise had no contact. Allison told me about, Laura, a grandmother with HIV, who was willing to hear more

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6 I did not, in fact, know any of the women's names or particulars until they themselves revealed them to me. I will make use of pseudonyms for the volunteers in the following discussion, however, for the ease of narrative.
about my study, if I wished to call her. I did, and after introducing myself over the telephone, Laura agreed to meet with me and tell her story.

I met the last two volunteers for the study through Allison, as well. As part of her woman and AIDS networking, Allison went to Vancouver Island to meet with the AIDS Vancouver Island's woman's group. I wrote in advance of her trip to the director and gained permission to post my advertisement at their organization. Allison offered to personally make my poster available at the private meeting she was attending. At our next B.C. Task Force meeting there was a reciprocal visitor from the AIDS Vancouver Island's woman's group. Allison introduced me to Heather after the meeting. Heather said she was willing to talk with me, so we exchanged addresses and phone numbers.

As a result of Allison's passing on my call for volunteers at the AIDS Vancouver Island meeting, I received a letter in the mail from a woman who said she had already gone public with her HIV status in her workplace and a local newspaper. She expressed interest in also speaking with me. I dialed the number given in the letter and first met with Julie over the telephone. We made arrangements to meet at a later date at her home on the island.

Allison proved to be a vital asset to my study by communicating information about my work within a confidential network of HIV positive women. The integrity of the women in protecting each other's privacy and identity demonstrated a high standard of conduct for myself as a researcher to maintain.

Interviews

An interactive approach between myself and the volunteer participants has been a central feature of this study, and has been encouraged throughout the three year duration of the thesis project.

One to three open-ended interviews were conducted, depending on the individual. Interview sessions were arranged at the volunteer's convenience and in a location of their
choice. Sessions varied between one and a half and three hours duration. These were
tape recorded and the volunteers each received a taped copy of their interview. Later, all
the tapes were transcribed into verbatim written text. To ensure confidentiality,
volunteers' real names do not appear in any of the taped or written materials. Pseudonyms
were selected by each volunteer and have been used throughout the text. In addition, I
have chosen pseudonyms to replace the names of friends or family members mentioned in
quotes used in the following pages.

Each person participating in this study has had her own reasons motivating her
involvement. I believe it is fair to represent that involvement as having two levels, one
personal and one collective. While the five volunteers' personal situations vary widely,
they are all similarly affected by the particular ignominy, ignorance and fear that comes
with being a woman diagnosed HIV positive. They are motivated as much by reasons of
the social context around them as by their own unique inspirations.

For my own part, my personal purpose has been to complete a Masters thesis in
Anthropology. On a collective level, my commitment is to the importance and beauty of
individual voices. My choice of topic represents a sincere concern for the cause of women
living with HIV and AIDS.

The volunteer's different personal motivations for speaking out about women and
AIDS resulted in five powerful interview transcripts. Although eloquent in themselves,
my responsibility is to contextualize their voices in meaningful academic and
anthropological terms.

Representations: Allison, Lynne, Laura, Heather and Julie

Perhaps the most frequent response to knowledge of a person's having
contracted HIV is, "How did you get it?" The significance of how an individual

7 The exception is Laura (a psuedonym), who chose to use her family member's real
names in her account.
answers this question reflects an important aspect associated with this disease.

Blame. The curious want to know the way someone contacted the virus because how they respond will be contingent upon such knowledge. Contracting the virus through a blood transfusion, tissue transplant, or serum, as is required by hemophiliacs, does not garner the same response as someone who has contracted the virus through intravenous drug abuse, or sexual, particularly homosexual, contact. There is a hierarchy of "victims" of HIV, some are considered to be more innocent than others. In introducing the five women who tell their stories in the following pages, I have purposely omitted to respond to the question of how they were infected. It is not a defining feature of any of them. Not wanting the reader to fall into the trap of seeing the participants in terms of their illness first, I have provided the following brief representations of the women that do not include explanation of the known or suspected means of their infection. I let the women tell their own stories in the following chapter.

Although this study focuses on circumstances and experiences surrounding their status as HIV positive women, it is important to keep in mind that the introductions offered here, and the later profiles, are but brief glimpses into the larger drama of the women's lives. These descriptions and quotes can only hope to, at best, imply their personalities and to suggest the fuller scope of their everyday lives and responsibilities. As a basis for their descriptions I requested standard details of personal history from each volunteer, including age, education, marital status, employment, and date of HIV diagnosis. Some specifics may have been left out or altered, as negotiated with the individual, in order to protect their identity and confidentiality:

ALLISON is a thirty year old, university educated professional. Married for just over two years, she and her husband live in a recently purchased apartment in the city. Since learning of her HIV status, Allison has given up her downtown job and does
freelance contract work from her own home. She devotes considerable time and energy to two AIDS organizations focusing on the concerns of women and families: one is a Task Force providing information exchange on topics relevant to women and children and the other is a grassroots organization aimed at directly assisting women living with HIV and AIDS. She is eight months pregnant with her first child.

Allison was diagnosed HIV positive in 1988.

LYNNE is twenty-nine years old and has long been active in organizations promoting rights for women and gays. Her educational background includes vocational training and she currently works as a full-time clerk in a medical services industry. Engaged and in the midst of planning a late summer wedding, Lynne lives with her fiancee in a rental home in an older city neighborhood. Aside from her involvements with the National Leather Association and the gay and lesbian newspaper, Angles, she is very active in a local Person's With AIDS (PWA) Coalition. She has participated in a "buddy" program, visiting PWA's in the hospital and, since her own diagnosis, has been involved with counseling and public education efforts.

Lynne was diagnosed HIV positive in 1988.

LAURA, fifty-eight years of age, is retired and lives with her husband in their family home in an ocean-front community just outside the city. She worked as a secretary up until a few years ago when she was forced to retire for health reasons related to cancer surgery. She and her husband of thirty-nine years have three children and five grandchildren. Just prior to her own diagnosis, her son, a professional living in the United States, was diagnosed HIV positive. Laura does what she can to educate her family and people she meets. While she has not had much contact with AIDS organizations, she was recently approached by one and has agreed to participate in education programming.
Laura was diagnosed as being HIV positive in 1988. At that time she was informed that she had been infected for the last six years since 1982.

HEATHER is twenty-nine years old and lives in the city with her five year old daughter. She grew up in a rural community where she completed grade eleven by correspondence. Heather ran a successful day care center from her rental home until recently when she lost her license due to her HIV status. She is divorced and currently depends upon a social service income to support herself and her child. After learning of her HIV status, Heather founded a support group specifically for women living with HIV and AIDS in conjunction with a local AIDS organization.

Heather was diagnosed HIV positive in 1987. After contracting Pneumocystis carinii pneumonia (PCP), she was diagnosed with full-blown AIDS in 1988.

JULIE is a forty-five year old health-care worker. Born and raised in Europe, she received her training there before immigrating to Canada in 1966. Since moving to the west in the early 1970's, she has worked as a psychiatric nurse in an acute care section of a large urban hospital. Currently she is on long-term disability from her job for health reasons related to HIV. Julie is single and lives with her cat, Pumpkin, on a property she owns with a large garden just outside the city. In an effort to educate others she has gone public about her HIV status at her workplace and in the local media.

Julie was diagnosed HIV positive in 1985.

In the following chapters, two levels of analysis will be demonstrated on the five stories provided. Chapter Two, comprised of a selection of quotes from the larger body of the complete interview transcripts, provides the first level of analysis. Chapter Three provides the second level through discussion of the major themes arising from the women's stories. The themes pursued are sources of information about HIV and AIDS,
contact with doctors and medicine, coping strategies, health treatment choices, managing social and intimate relationships, financial implications of being ill, and speaking out about women and AIDS. Both personal and social influences affecting the women's lives and livelihoods are investigated. The final chapter, Chapter Four, returns to the women's voices. During the three years duration of the study much has happened to those who share their stories here. Chapter Four, providing significant emotional and descriptive time-depth to the documentation of the women's experiences, updates their individual situations two and a half to three years after their first interviews.
CHAPTER TWO
LIVING WITH HIV AND AIDS

Printed transcripts of the taped interviews conducted with the five women in this study amounted to approximately two hundred and fifty pages of single-spaced text. The transcription process was a laborious and time consuming task. With assistance from my husband who transcribed half of the tapes, all the interview material was transferred from the tape cassettes to the computer, using my small hand-held tape recorder, many batteries, and almost constant action of the forward and rewind buttons. Once the text was entered into the computer, I went through all of the tapes again, by myself, matching voice to written text in an effort to achieve a verbatim representation of the spoken words.

Spoken conversation is, of course, much different from written text. It is rich with inflection, repetition, pause and incomplete utterances which, along with intonation, expression, and body language, convey instantaneously what the written word can rarely achieve. My strategy in attempting to follow as closely as possible to the spoken word as it was captured on the tapes, has been to offer as honest as possible a representation of the individuals as they speak. To this same end, I have chosen to present each woman's story as a complete vignette, rather than separating their voices in order to follow a common theme, such as their different responses to medical treatment or relationships. This holistic format allows the reader to best sense the personality of each woman and, in turn, best allows the integrity of each woman's experiences to be maintained.

In presenting the five vignettes, I have tried to retain a standardization of format that generally follows the outline of the interview questionnaire that directed the original interviews (See Appendix 3). As all of the interviews tended to follow this format, a minimum amount of editorial intervention was required in ordering the quotes selected. In most cases, uninterrupted quotations have been selected. In some cases where, for
example, the volunteer spoke about the same topic in more than one place, sentences from several areas in the interview on the same topic may be placed together. Where editorial intervention was required to make proper sense of a passage, words or inclusions appear in brackets within the particular quote. Rounded brackets ( ) enclose an aside or interjection from the speaker herself. Squared brackets [ ] enclose words, explanations or, omissions for the sake of confidentiality added by myself as editor.
Allison

Although I had known Allison for over six months and we attended many of the same BC. Task Force meetings, the day I interviewed her was the first time I had visited her home. She lives with her husband, David, in a low rise apartment building in a well established city neighborhood that slopes down towards the water. On the morning we had arranged to meet it was raining. I stood in the shelter of the entrance to locate Allison's family name on the board outside the front door, and rang the buzzer. Allison soon appeared in the foyer to let me in.

It was a friendly meeting. I noticed since the last time I saw her that Allison's small frame was transformed by her pregnancy. At eight months into term, the front of Allison's denim jumpsuit was round and full with the promise of her soon-to-be-born child. I commented on how well she looked as we entered her ground floor apartment and we laughed together as she demonstrated the difficulties of bending over.

Allison made some tea for us, herbal for herself and regular for me, while I looked about the living room. Mementos from Allison and her husband's travels decorated the bookshelves and walls. Allison does consulting work from her home. So we would not be disturbed, Allison turned on the telephone answering machine in another room to take calls. We sat at the kitchen table.

Allison had already looked over the volunteer consent form and signed it. On this occasion I gave her back a photocopy of the form, for her records. For my information she passed on to me a tape cassette of an anonymous interview she had given in 1989 on CBC radio about living with HIV. I planned to transcribe this tape as well as my own interview with Allison for use in my study. Although I did transcribe this earlier interview, I ended up not using material from it. Our interview was much more in depth than the radio spot and covered more ground, in particular Allison's thoughts and decisions associated with her pregnancy.
With the assurance of confidentiality, Allison was happy for the opportunity to talk of her personal experiences living with HIV. A thoughtful and articulate speaker I imagine she suffers considerable frustration participating in activist and support work for women and AIDS while remaining secretive about her own status. She conducts herself in a matter-of-fact and professional manner. The confidence that carries across a conference table is present here from across the kitchen table too, but there is also vulnerability. Perhaps it is just my own impression of seeing her in her own home. Allison is the same age as myself and we have much in common. I am anxious about her health and the potential health of her unborn child. What she and her husband must bear through this time is hard to imagine. We do not speak of these things. She appears relaxed and collected, as always. I knew that she had another appointment for later on that morning. We had one and a half hours to complete this session.

I set up my small tape recorder between us on the marble topped table. I began by asking Allison if she recalled the first time she ever heard about AIDS. She said she thought it was sometime around 1985. She heard about the screening of blood for AIDS by the Red Cross:

The thought flickered through my mind. I wondered if there was any possibility that I might have it, or have contracted it, because I had this one relationship with a guy who was bisexual. It really just flitted through my mind and then it flitted right out again. I really never thought about it any further. I didn't feel that it touched me at all. It wasn't one of the major issues of my life.

Unfortunately, for Allison, this was to change. Three and a half years later, in November 1988, on the way home from work she saw a blood donor clinic and decided to drop in:
I just happened to be walking by a clinic, a donor clinic, and I thought, Oh, I've got some time. I'll go and donate some blood. I came out feeling good about myself for having made my social contribution. About three weeks later I got this call from the Red Cross saying, Could you come in. We'd like to talk with you and take another sample of blood. I think I actually had to come out and say, Is it the AIDS virus?

Allison vividly recalls the moment of her diagnosis. Small everyday details of time and place were rendered suddenly significant and unforgettable at the borderline between her life before HIV and the life she lives now:

I was at work. It was probably about 4:30 in the afternoon on a rainy December night. I had to go somewhere else and pick something up, and I remember I was traveling on the bus. I have a very vivid image of that evening, traveling on the bus, sitting on a side seat, the single seats, looking out the window and, of course, it's all fogged up because - you know how it gets when it rains and all the lights outside..? It was dark and all these bright neon lights reflecting off the street, and sort of sitting there feeling only half real and that this was a dream I would wake up from, and yet the other half of me knew that it wasn't. I was just somewhat matter of fact about it. I realized that it was possible it was a mistake. It could have been a mistake. I guess in one way I suspended all belief and all feeling for a while, because I had to let it go through my mind a bit before it could really sink in.
It wasn't until she got to the safety of her own home that Allison could dare to contemplate what she had been told. As soon as David arrived she told him. He was very supportive and they went to the Red Cross together the next day for a retest.\(^8\) David tested negative. Allison tested positive again:

I went to work right away. I couldn't think of just going home and sitting and moping. I didn't know what else to do. I had to go on. I had commitments to make, meetings to go to and deadlines to make. I went to work and it was a miserable day. I didn't get much done. I thought about it in the course of doing all the rest of the normal things that I would have been doing in my life. I decided I would contact a counsellor and just talk. I needed to talk. I didn't have any information, but more than information I just needed to get it off of my chest and share it with somebody.

Allison and David had spoken to the doctor at the Red Cross for about an hour and half that morning. The doctor had recommended that Allison get in contact with a counsellor at AIDS Vancouver. The counsellor was helpful in providing understanding and information. As Allison and David had only recently moved to the west coast from back east, Allison did not have a family doctor yet. The counsellor was able to recommend someone and advised Allison to make an appointment to take further blood testing. To Allison the most important thing the counsellor gave her was the phone

\(^8\) The test the Red Cross uses to screen all donated blood for HIV is called the enzyme-linked immunosorbent assay test or ELIZA test. It is inexpensive, rapid and easy to use (Spurgeon 1988:36). A non-reactive, or negative, result from an ELIZA test very accurately demonstrates that a blood sample contains no HIV antibodies. A reactive, or positive, result, however, may sometimes be false and is always repeated more than once. A consistently reactive ELIZA test can be confirmed by one of several confirming tests, usually the Western Blot (other tests are the immunoflourescence assay, IFA and the radio-immunoprecipitative assay, RIPA). The Western blot test distinguishes samples that are true positives from those that are falsely positive (Pinsky et al 1992:7-8).
number of another women who was HIV positive. Allison met with her just before Christmas:

The counsellor put me in touch with this other woman who was HIV positive and I met her. She was marvelous. She was so positive. She had a very strong sense that one could do things for oneself. Because she was the first person that I met who, in any capacity, was able to give me some concrete information about what it was like to live with it, I was very buoyed by that. Psychologically, it was a very good thing that I met with this woman before, for example, I went to the doctor for tests and discussions and blah, blah blah. Because it completely cemented my attitude and my resolve that I could deal with it. I feel that that's what happened. I probably was susceptible to a whole range of possibilities at that point, but because that first person I was able to deal with was somebody who was herself positive and doing things that were helping her, I felt I could do that for myself too.

Allison credits this early meeting with another HIV positive woman as providing her with the resolve to find a meaningful way to carry on with her life. The woman was living proof that being HIV positive was not an immediate death sentence. Allison also felt optimistic because this woman was coping well, even though her immune system was already compromised and she had experienced some medical complications. Allison felt at an advantage since she was not even sick. Despite the inspiration the woman provided, however, Allison still suffered a period of severe depression:

I thought I was coping quite well, but I had been dragging my butt a bit and I wasn't able to find too much to be joyous about in life. It was a
difficult time. There are a lot of things that go through your mind. I mean, as much as anything I am a person who likes to have information, concrete facts and information to deal with a situation and, in some ways, I wanted the information first before I started making any decisions about how I was going to deal with things. It wasn't that I consciously said to myself, How am I going to deal with this? But it's just that it kind of happens, because how you deal with things is how you live. About the end of January, the beginning of February, I started to snap out of it and I was starting to feel a little bit more informed about the whole issue. I had done some reading, such that I could, in-between working and everything else. I became more knowledgeable as time went on about how HIV affects your body, and about where my body was at in terms of... What the status of my immune system was.

Finding out information about HIV and AIDS was one way that Allison found to help herself. Newspapers, medical journals, popular magazines and books, provided ample material about AIDS. AIDS Vancouver had a collection of reference materials.

To find out the status of her immune system, Allison went to see a blood specialist at the hospital who conducted a whole spectrum of tests on her blood. The tests established a base line of information that subsequent tests would be compared to, in order to gauge the effect of HIV on her system. The most important test for doctors, Allison explained, is the T-4, or helper cell, count. In British Columbia a person qualifies to take

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9The T-4 lymphocyte count, or t-4 count, or simply T-4's, is the prognostic marker most commonly used to measure the immune deficiency of HIV disease. The test measures the absolute number of T-4 lymphocytes per unit volume of blood. While values vary, a healthy person's count can range between 600 to 1400. After HIV infection the T-4 cell count usually drops below 800 and continues to drop smoothly and steadily downward at an average drop of 40 to 80 per year. As immune deficiency worsens, the drop may be accelerated. Most physicians recommend anti-viral medication to persons with T-4 cell
AZT when their T4 cell count falls below 300\textsuperscript{10}. At the time of her testing, Allison's T4 cell count was just around 300.

While the information Allison received from her doctors gave her a picture of how her body was coping with HIV physically, they did not provide her with a way of dealing with her everyday life. Again, Allison found her early contact with another woman living with HIV useful in providing insights into strategies for coping on a day to day basis. Key to her strategy for coping was regaining a sense of control over her life, otherwise diminished by her illness:

One of the things this woman whom I had met who was also HIV positive had told me about, what she was doing a lot of was what she called "mind-body healing". Essentially, it is using the techniques of self-hypnosis. Using your mind to help heal your body. So, I found that intriguing. I did some reading on it, some of it was guided by her, and some of it was just on my own. I read Bernie Seigel's book, Love, Medicine and Miracles, that was recommended to me. It's about cancer patients who have cured themselves - quote - of cancer. A lot of really positive stuff. I felt that people are doing this, why can't I? Essentially, that's the course I began to follow last year and I've been pursuing it ever since. Whatever medical science has to say about these, somewhat unproven by scientific standards, techniques like self-hypnosis, mind-body healing, I have a sense of control over my body now. It seems to be working.

\textsuperscript{10}Since the writing of this study, the criteria has changed in British Columbia and a T4 cell count of 500 qualifies an individual for AZT.
Allison found she had to make some changes in her life, even in her personality, when adjusting to living with HIV. She made it into an self-empowering, rather than a victimizing, process:

It's sort of interesting because, I think you'll hear this from any people who are faced with a life threatening disease, that all of a sudden it forces you to reassess your priorities and say, Hey, what is really important to me? Then you start thinking, Why am I getting so excited about something that isn't that important? Or, Why am I spending my time doing this if its not that critical? We should all live our lives as though we were going to be run over by a truck tomorrow. And when I say that I only mean that you have to give the best to each day that you have and then you never feel that badly about the last day that you have. It allows you to say that, I did the best that I could. So, I'm not going to really think that today was a wasted day, even though I didn't get everything done that I wanted to. You look for something good that happened in each day. That's what I'm really trying to start doing. Looking for something in each and every day that is good.

Actually, it may sound.. its very simplistic to say that.. It wasn't easy for me to do that, because I wasn't the person who would.. I wasn't the little ray of sunshine in everybody's life. I've been quite a moody person over time. I have, and do, let things get to me. I fret over things I shouldn't fret over, but I made a concerted effort beginning around February of last year, about three months after I first found out about this, Okay, its time I got on with my life. I still have a lot to contribute. How am I going to live my life? I'm going to live my life the best I can, given
what I know. That's when I started looking for something positive in every
day.

It's almost...actually, going through the depression was good
because I tended to be oblivious to the good things during that time, but
after that I was able to get up and look out the door and see that it was a
fresh, crisp, March day and the snow was sitting on the mountains and they
looked like they were right next door. You know how it is when there's
sunshine in Vancouver? It's wonderful. I would feel wonderful about
something little like that. About hearing a bird singing in the back yard or
running into a friend and having a nice lunch, or even something as trivial
as making someone smile on the bus. That's how I coped with it.

Coming to terms with being HIV positive and finding a way to reorient her
thinking for the future are intensely individual processes with which Allison continues to
struggle. A significant influence upon this self-journey includes the response and support
of those around her. Allison was diagnosed only shortly after she and David were
married. His initial supportiveness aside, because David tested HIV negative, Allison tried
to prepare herself for the possibility that he might rethink his option to stay in the
relationship:

Really, I was prepared for anything. I was prepared that he would
decide he couldn't cope with it. We'd only been married for two years. It
was a lot to ask of someone that you're just committed to spending the rest
of your life with: that they commit themselves to spending the rest of their
life with somebody that's possibly not going to be around, or possibly could
pass on a life threatening illness to them. I had to be prepared. In my own
mind I understood that if he made the decision that he wasn't strong
enough to deal with it, that I would have to accept that. I knew it would be really difficult and for a while there it was really touch and go. I didn't understand how he really could leave the relationship, but I was prepared to let him go if that's what he wanted to do. He was able to work it out in his own mind that he was in a good place in terms of relationships. He wanted to stay.

David's wholehearted and unconditional support is an important aspect of Allison's well-being. Allison had to inform her family of her HIV status over the telephone, as all of them live out of the province. She empathizes with her parents response of shock and sadness:

They were really upset. They didn't know really... I think that any parent when hearing about something happening to their kid that may threaten their life, it must be devastating. They would be touched by it on a very emotional level. I'm sure for different people it's different. Some people would be more concerned with the fear they would feel because they don't know much about it. I think my parents just were upset because they've never had to deal with anything like this before. But they really love me and they continue to do so. There was no sense of rejection.

Dealing with the response of others, even when that response is not something negative, can be a burden. Allison explains that coping with another person's trauma and grief at the news of her illness is a factor she has to consider when planning to disclose her status:
It's hard for people to hear that you have HIV. Mostly they don't know much about it. They know something, but what they know is generally more frightening than comforting. And so I feel that when I tell someone that I have this, that I have to tell them that I'm okay, too. It's okay. Don't cry for me. On the average that takes from one to two hours, at least in my experience so far.

Allison is very selective about who she tells, and who she doesn't, about being HIV positive. One of the risks she tries to protect herself from is being identified in terms of her HIV instead of as a person:

More than anything I don't want people to feel sorry for me, because I don't feel sorry for myself. I don't want to go through my life being pinned down. I don't want to go through my life being identified as the person with HIV, because I feel that there is so much more to me than that. It's just one part of my life.

Allison had much to say about her relationship with her husband, and how this had been changed by the decisions they have made together since she was diagnosed:

It has brought us closer together. I think he, as I, has realized that every day together is precious and every experience is precious. Not that we go through life thinking always about this, because we don't anymore. We did for a while. It was very, very prevalent in our thinking, but we've gone on to other things now. It's in the background, but what it does is, it enriches our lives. It makes us appreciate everything we do together. In
the physical sense we have had to make some adjustments in our sexual lives, but that has not been a problem.

Safe sex requires changes in attitude and practice. Allison describes that knowledge, perseverance, and patience are helpful in dealing with the stresses of having to alter patterns of intimacy:

I thought it would be more of a problem than it was. It's an ongoing thing. We certainly didn't come to terms with that right away. I wasn't even comfortable with, you know..latex before, but you get used to it after a while. And the more information you have the easier it is to deal with. I find that the more information I read about safe sex and what is safe sex and what isn't..the more I read about it, the more comfortable I am about the idea of safe sex. And David has sort of followed along. It hasn't been easy for either of us. Its evolved. I mean we didn't just throw up our hands at the first try. We've just sort of kept at it. It certainly hasn't narrowed our concept of sexuality. If anything it has broadened it, and that's been good. There's definitely a learning curve.

I think one piece of advice I would give to people who find themselves in the same situation is not to be afraid to seek out professional help for any kind of problem you have to deal with. There's certainly no shame in not being able to deal with things yourselves. Another thing is it doesn't happen over night. I mean, we're talking a year and a half since I first found out and we're still working things out. But if you understand that its not going to get better over night, that its okay to be upset, its okay to not know for sure whether you're going to be together for a long time, its okay to take life one day at a time. Not only is it okay, it is almost
essential. Only that way I think can you cope with all the different things.
You don't deal with one problem at a time, generally speaking, you know.
And then this thing throws all kinds of different problems at you all the
time.

One of the problems that Allison had to confront was the possibility of having
children. Allison and David were thinking about having a family just at the time she was
diagnosed. The change meant that they had to rethink their options:

For a while we thought about not having kids at all. I really didn't
know if I could do that. I thought, well, okay. I'm prepared not to have
kids biologically, but I'd like to have kids some way - through adoption,
through fostering, or something. It became apparent, I didn't do a lot of
inquiring, because of my physical condition. It is so difficult to adopt kids
anyway, even if you're healthy. So I thought, Oh, gosh, I'm not going to be
able to adopt a kid! And I haven't had any children of my own, so the idea
of fostering a child that may have emotional problems or other kinds of
problems that are common with foster kids, I was a little bit nervous about
that. And, also, there's my husband to think about. I think I was more
prepared to deal with problem kids that he was. It didn't deter me as much,
but if we were going to do this as a partnership then we both have to be
100% committed. I wasn't clear in my mind that he would be committed to
that route. So, we talked some more about having children and I did a lot
of research.

Allison went to her doctors, specialists, and the library to find out what they had to
say about pregnancy, childbirth and AIDS. The risk involved is perinatal transmission or
infection of the child with HIV through the mother during pregnancy or childbirth. While the little information available would appear discouraging to many, and the common attitude of medical practitioners at this time was to discourage pregnancy, or to recommend termination of pregnancy to those already pregnant (Anastos & Marte 1989: 10), Allison weighed the evidence and made her own decision:

I did a lot of research to find as much information as I could on the statistical risk and probabilities and so on. What specific factors would contribute to risk. I came away from that feeling, yes, there definitely was a risk, a significant risk. The statistics I was able to find were showing rates from 15 to 50% (transmission of HIV to the baby) roughly, depending upon the study. The problem with all the evidence I could see was that most of it was done either in New York City on women who were poor, drug abusers, or minority women, economically, and probably physically compromised as well, or African women who, again, you are dealing with people who have a socioeconomic superstructure that is completely different than mine. I felt in terms of what the statistics were saying, that I was probably on the better than average side of the statistics because of my access to health care, my knowledge base and so on. And, secondly, I looked at the statistics and thought Okay, supposing you have a 30% chance of passing it on. Well, that's a 70% chance of having a healthy child, isn't it? You know, for me, I thought, I'm a bit of a risk taker. I guess I'd be willing to take that chance.

The decision to try to have a child was, of course, not merely a matter of academics. Allison had to consider all the consequences, including the possibility that her health might be seriously compromised or that she would give birth to a baby that might
itself die from AIDS. The decision is a tremendous one to carry. Allison would not know if her baby was free of HIV until six to eighteen months after its birth, when the effect of the antibodies she passed on to her baby wear off and the child's own immune system takes over:

Both David and I had to think of it in terms that were not just risk statistics, but very personal experience. So, you have a kid. What happens if the kid turns out to be HIV positive and dies on you after the first year? I thought, Can I deal with that? I've got a fairly good imagination, so - yet I don't pretend to say that I knew what it would be like if that kind of a situation would happen - I just knew that I was prepared to deal with that. And I understood even in making that decision that I would be putting myself at risk for some phenomenal hurt, but I also, in the back of my mind, knew that if I did not try it, if I didn't take that risk, I would always wonder whether it would have been possible. And I wasn't afraid of the pain I might feel about losing a child. I decided that any part of the experience, for whatever the experience is worth, for me, it would be worth it. Even if the child lived only a year. I wasn't prepared to pass judgment on the value of my child's life, but I knew it would be an enriching experience for me whatever the circumstances were and I was prepared to do my damnedest to make sure that it worked out to the best. And here I am, nearly eight months pregnant, and I still don't know and I won't know for nearly another year what the circumstances of my child's health are. I am very confident that I have done the best that I possibly could, and will do, to make sure that my baby is born healthy. Even if it isn't born healthy, I'm going to love it just as much and make sure that its life is every bit as meaningful as the next child's, the next person's. That's
really the only way that I personally can cope with that decision, to know
that I was going to make the best of it. But I'm confident. I'm fairly
confident that I'm going to have a happy, healthy baby. The other thing I
can say about my pregnancy, I am very aware that my decision to have a
baby is controversial in some people's eyes.

Her own and her husband's feelings aside, Allison is concerned about other
people's attitudes towards their decision:

I'm sure that there are people out there who would feel that it
shouldn't be for me to put another life at risk, if you know what I mean. I
mean, this little baby is a separate person, it's not me. Do I have a right to
put someone else's life at risk like that? I don't pretend to have an answer
to that one. Obviously, for myself, I made a decision. I'm not going to
counsel anyone else to do anything else, either differently or the same as I
have done. I think everybody has to choose for themselves, with abortion
or any other controversial issue. For me, having a child is a very important
part of fulfilling my personal goals. That's why I - we - came to that
decision.

The possibility of criticism or harassment to herself or her unborn child adds
urgency to Allison's wish for confidentiality about her HIV status:

Because of the fact that I realize it is a potentially controversial
decision, I am very protective of my baby's status and therefore, at this
point, particularly of my own status. I'm not prepared to come out and tell
people about it until I can completely trust them. I don't want to create
undue stress for myself and I don't want to risk my baby's confidentiality.
The child has a right not to be pin-pointed as an HIV baby. We'll see what happens. It's quite conceivable that it will be a perfectly healthy child and, in that case, I don't want it to be subject to all sorts of potential harassment and discrimination.

Allison also had concerns about the response of her doctors to her choice of action:

I found that the doctors I spoke with were definitely swayed by the prevailing medical line which is that women who are HIV positive should not have children because the risk of transmission is fairly high. I knew I was going to run into that resistance so it didn't phase me particularly. I found it a little frustrating because all I was really looking for then was information. I knew that ultimately the decision was mine to make, not theirs, and I would take their opinions into consideration, but basically I would make my own decision. I made my decision based on the information that was available, which I just told you before, I felt that I was better than the statistical risk figures were showing or I had a better chance. But I found after I made the decision to get pregnant, I told my doctors (I have many of them), that they supported me wholeheartedly and did everything possible to both get me information and make my passage through the system easier, and help me find the best of medical care.

Allison has an excellent working relationship with all her doctors. She takes an active, rather than a passive, role in her own health care. She takes what could be called a consumer's approach to health care. It is not uncommon, she tells me, for her to get a
second opinion on health issues. This is not meant as criticism, but rather an effort on her part to inform herself of the prevailing views. She finds that many doctors do not have much experience with HIV among women. As much as possible she tries to work with her doctors, passing on the latest journal articles and medical information she has located, and attempting to recognize the doctor as a person, as well as a professional. Allison hopes that her investment in time and effort into her relationships with her doctors will be reciprocated:

I think of my family doctor as my primary care physician and that's where I go first if I have a problem. If she can't satisfy my curiosity or alleviate my concerns, I'll pursue another line. But I must admit I've taken a very proactive role in my own health care. I've definitely made it my own health. If I'm not happy with what my doctor tells me I'll either pursue it by going to do some more research or by asking someone else's opinion. I think you really have to do that. I mean, let's face it, doctors are only human beings. They only have a finite amount of time to do research and they have a dozen different patients and problems to be familiar with. You can't expect them to devote all their time to researching your particular problem. Whenever possible I give my doctor, my family doctor, information on AIDS, so that she can be informed, as I try to be myself. I know she appreciates it. I also try and make sure that I have human relationships with them as well as professional relationships, as well as the client-patient relationship. I try...I make a very conscious effort to ask my doctor how she is doing and how is her family life, and so on, so it is just not a one way street. I want her to realize that I look at her as a person because I think in reaching out to somebody, whoever they are, you make
that connection with the person and then they see you as a person in return.
For me that is really important.

Allison's proactive role extends beyond doctor's office when it comes to a health regime. She makes use of several alternative medical practices, including consulting with a native Indian healer. She has found alternative medical practices more encouraging than traditional medicine, especially in that their diagnosis tends to involve recommendations about what to do to improve one's condition, as opposed to diagnosis of how poorly one is doing. The difference may seem only one of perspective, but it involves key life-affirming aspects of hope and control. For Allison, the results speak for themselves:

I was feeling very comfortable with my meditation and the mind-body techniques I was using. I actually felt better than I ever have in my life. I have been very conscious of my physical fitness and my nutrition and general health and so... Actually my clinical markers, as they call them, my blood work, has been showing improvements, other than decline, which is what they normally would expect if you are not on any sort of medication. They expect you to get worse. I wasn't getting worse. I was stable.

Allison is concerned about the lack of public profile of women with HIV and AIDS. The general perception that AIDS is not really a women's problem results in ignorance, fear, and lack of appropriate services for women who desperately need support and services. Allison, like many others, feels that women with HIV and AIDS coming forward into the public spotlight about their needs and concerns would have a positive impact on the problem. The nature of the secrecy and stigma inhibiting such action is revealed in the language used to describe the process. Allison speaks in terms of women
"coming out", a term usually used to refer to a gay person's public revelation of their sexual preference:

Being a woman is difficult in some ways. There are so few other women available to talk to about it. I think that more women need to come out. I feel on the one hand moved to reveal my story, on the other hand (pause) not guilty so much...chicken, perhaps because I want to protect myself as well. I certainly know that if I were to come out and speak publicly about it, I would get a lot of attention. In some ways I would be a good candidate to come out because I am reasonably articulate and I have a strong sense of social obligation and I feel very strongly that I should do something about it, but I also have to live my own life. Right now it is more important for me to do that. The other thing about it is, if you come out and speak about it you can never go back and be your own quiet little person, so you don't want to do that too soon or without a lot of thought first.

Allison is appreciative of her own situation of emotional and economic stability. She suggests, however, that not recognizing that women too are at risk of HIV and AIDS can have traumatic repercussions on individuals when they are diagnosed:

I have never, ever encountered prejudice, or reluctance to help for that matter. But I think it is very difficult for women because there are so many characterizations of this illness - disease, condition, whatever you want to call it - that exclude women and exclude some of the things that women are concerned about. I think it is really important for women who are testing positive to be able to feel that they are not alone. I think there
are a lot of women out there who are feeling very alone and not knowing how to cope, and feeling angry because its not their disease somehow. That its not fair that they got it. Its not like that really, it shouldn't be like that. I'm very fatalistic about it. You get what you get: the hand that was picked for you. You have to make the best of it, whatever it is. But it helps to have support. I've been very lucky. I've had lots of support. I think I'm doing very well so far.

The need for support and services are constant themes in Allison's discussion about women living with HIV and AIDS. I asked her about what services she has used and how helpful she found them. What she does not say is that her own efforts in committee work and organizing for women and AIDS is considerable:

I think because I had so much support from my husband and family, I perhaps needed less in the way of outside support than otherwise. I found the People With AIDS (PWA) Society very helpful whenever I've tried to use their resources or access them. I know they have a lot of people who are really good at support there. I haven't really needed to turn to them. I mainly use them for information and they have lots of that, too. Very welcoming people, too, I must say. Other than that, I have really tried to go out on my own and make connections with people. There are a number of groups around town that are working toward working for women with HIV and I've associated myself with those groups, so now I have access to those resources. You know, there're are a lot of really wonderful people out there who are putting a lot of volunteer time to it, to find women who are HIV positive and help them.
One of the main areas not adequately provided for in most AIDS organizing is support for family concerns, in particular issues surrounding childbirth and children. One of the issues for HIV positive women is concern over whether they might be able to ever have children. Even if a women might not have considered childrearing before, the thought that there might be obstacles imposed can inspire grief, depression, or a sense of loss:

I think a lot of the issues are family issues, the notion of having kids is a big one. Its more than a women's issue, but its somehow uniquely a woman's issue, too, because for many of us our fulfillment is tied up in our reproductive role whether we chose to use it or not. Some of us chose not to use it. Its funny when something is taken away from us, you think - Hey, wait a minute, maybe I wanted that after all!

In British Columbia where the official number of women infected with the AIDS virus is still relatively low compared to the infected male population. Allison remembers the importance of her early contact with another HIV positive woman:

There are a lot of women who are HIV positive who do not know where to access each other because there is no natural community. That's difficult because whenever you are isolated and alone and dealing with something, it is so much harder than if you have some support and help. I'd like to.. One of the reasons why I'm involved with these women's groups - the women's groups helping, looking out for HIV positive women - is that I think it is really important to make those connections with other women. I'd like to be able to lean on and be leaned on.
While safe sex is widely advocated, Allison feels that more information should be available about what safe sex actually is and how to practice it. More dialogue on the subject is the minimum effort required. Allison suggests a whole pattern of social behavior needs to be altered so that women can have more control over their lives and their bodies:

It would be nice if there was a place where you could find information that pertains to how HIV effects women's bodies, how HIV can be dealt with sexually, not just for people who already have the virus, but for those who maybe want to try not to get it. How do you deal with sexuality in the face of HIV? That's a really tough one. Our society has so many hang-ups about dealing with all kinds of sexual things to begin with. Throwing this one on top does not make it any easier. I'd like to see, I don't know exactly how it would be done, but I would like to see some kind of a new sexuality for women. An exploration of the topic. I mean, how can women deal with taking charge of sexual relationships, so they can prevent themselves from being put at risk? We can't let men direct our sexual relationships. If they have strong opinions about it one way or the other, which generally speaking men do (more than women, I think) I mean, within relationships. Oh, I'm generalizing. I think a lot of women probably can take control of their own sexual relationships, but I think there are a lot of women that don't and can't, who feel inhibited or afraid to even ask a man to use a condom or don't feel comfortable about it, or laugh about it, or can't go to the store and buy them. It doesn't have to be that way, only it is hard to deal with that on your own. Its nice to be a be to
say, well, here's one way that I can do it because so and so did it that way.

Or even little things like eroticizing condoms.¹¹

If safe sex is the way of the future, then steps must be taken to remove its presentation from the antiseptic realm of medicine to a more sensually appealing genre:

One person, one women, I know who is HIV positive told me that she likes to keep her condoms in a really nice container beside the bed, you know, a nice pretty, little container. I thought, that's a really great idea. It's so much nicer than reaching for this sanitized box with a picture of, you know, a sunset. The packaging for condoms is pretty sterile and medical, you know what I mean? It's hard to eroticize safe sex. Who in their right mind today feels comfortable about going into the drugstore and buying rubber gloves? There are a lot of inhibitions about it, and being able to deal with that, such a resource is non-existent for women of any stripe.¹²

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¹¹ Condoms and lubricant are standard equipment for safer sexual contact between partners. Condoms of different varieties are now commonly available e.g. thin ones suitable for vaginal sex, heavier ones for anal sex. Dental dams, originally invented for use in dental surgery, are now recommended for oral sex on females (O'Sullivan 1992: 270). As one of the goals of safer sex is to avoid contact with body fluids, commercial lubricants are necessary to use as a substitute. Water-based lubricants are recommended since oil-based products degrade latex.

¹² Similar to condoms, latex gloves are used to protect one or both partners from contact with potentially infected body fluids and to safeguard the health of the HIV positive partner. In this case, David wears rubber gloves to protect himself from any chance of infection through contact with Allison's vaginal secretions. Although there is no clear evidence to suggest that a person can become positive from finger contact with vaginal fluids, except theoretically through open sores or cuts, the use of gloves is a safeguard that relieves worry for those concerned (O'Sullivan 1992: 271). Equally as important as protecting David, wearing latex gloves helps to protect Allison from the harmful effects of any germs or bacteria entering her system.
Allison's confident manner falters somewhat when I ask her whether she has considered the possibility of her dying. It is a difficult question for me to ask and, obviously, not an easy one for her to consider. Since the moment of her first diagnosis she has been dealing with just such a possibility. She has found within herself a means of building for a future, including her hopes for the child she caries within her:

I would say that in the last year I have not dealt with it fully. I thought about it and put it aside. I made a decision, I'm not going to die, basically. I do not want to die for another twenty years, so I'm not going to think about it. On another level, I think I am ready to deal with whatever comes next. As long as I'm healthy. I have this mind set that I am going to be healthy for the next. - I arbitrarily picked 20 years because it is an easy nice round number - and so I said I'm not planning on doing any (pause). I'm going to be around for the next 20 years, is what I say to people if they ask. So, I am not ready to die. I am not so much afraid of death, because I believe in. Part of me believes in reincarnation, part of me also accepts that when you die there is something more, something beyond, something greater than what we're doing now. Here. For me, I don't really. I'm not afraid of death because I don't see it as the end. So..I mean, its hard to say. Maybe my opinion would change if all of a sudden I discovered that I was getting sick, you know? But I.. As I said before, I am living one day at a time and I'm going to enjoy every day as it was my last. I would like to be able to say that when I leave, people will think well of me. That's as far as I can get with it at this point. I try not to be afraid of it. I'm not afraid of it at this point, but I am also not convinced that I have fully dealt with it, because I'm not at the stage where its confronting me face to face.
For me the way to deal with it has been to say, okay, the potential is there for it to be life-threatening. But what is not known, it's almost like no news is good news. The total experience of AIDS is ten years and I can't look beyond that because there is no previous history to go on. All I can do is say I'm planning to be around in 20 years and maybe by then they will have found a cure. That's how I choose to live my life. To look for the positive things. Some days I get.. I have thoughts about it, not morbid ones, but I'll think, you know, I might not be around..not specific times..but, for example I've talked with my Father about the possibility (pause) that I might die before he does. I don't think he is very comfortable with that idea, but I've accepted that., that possibility is..there. Now, if I really have to face that, then I will cross that bridge when I get to it. For the time being I choose to look only to the positives because I think if I'm looking for the positive things, I'll find them, and if I look for negatives, I'll find those too. So, I'm not looking for negatives. I've chosen not to look for them, but when I have to deal with those things I will deal with them. I am prepared at least that much, to say that when it rears its ugly head at me, I'll look it in the eye and deal with it. But for now I am only considering the positives.
Lynne

I met with Lynne in her own home early one spring evening. I arrived by taxi to the door of the comfortable house she and her boyfriend rent in a quiet, older city neighborhood. We had set the time for around seven PM, to give Lynne a chance to unwind after work and have her dinner.

Lynne welcomed me in. She directed me through the living room to the kitchen, where she wished to conduct our interview. She made tea, moving around the kitchen from the cupboard, to the sink, to the counter, as I set up my tape recorder and note pad on the small arborite table in front of the kitchen window.

This would not be Lynne's first interview about living with HIV. A year earlier she had given an interview about being HIV positive to a reporter from a small local paper. She was not pleased with the way it had been handled, feeling that she had been a bit manipulated and that she had not had sufficient control over what eventually was printed. Lynne made this known to me and then, together, we reviewed the consent form I had brought and discussed the terms of our interview process. Lynne explained that she felt confident in giving this interview because the terms appeared to safeguard her concerns about shared involvement and editorial control over the taped interviews.

By raising the issues of responsibility and control at the beginning of our session, Lynne set the tone for our future collaboration by emphasizing not only the cooperative nature of our partnership, but our different roles as well. This helped to put us both at ease by directly addressing the formally contrived nature of our meeting. That we were not real friends, with a history of shared knowledge and understanding between us, would soon be easy to forget as Lynne revealed the intimate details of her story.

Cradling our cups of hot tea, we began the interview. In her soft, even voice, Lynne spoke about the events surrounding her diagnosis, her past and present relationships, her family, her health regime, her hopes, and her fears. She was open and
frank about her feelings and experiences, creating an atmosphere of closeness and trust between us. We had spoken for forty-five minutes, filling one side of my ninety minute cassette, before I realized that I had not set up the recorder properly. The tape was blank.

It was a considerable setback for the both of us. I was extremely disappointed and embarrassed. Lynne must have felt just as disappointed, even betrayed. The error broke the atmosphere of our discussion. Lynne got up and made another pot of tea. We talked off the tape for quite some time before Lynne suggested we move to the more comfortable chairs of her living room and start again. I suggested that we briefly review what we had covered previously. Lynne demurred, saying that she was tired and preferred to continue from where we had left off.

After my most careful attention to the workings of the tape recorder, we continued our discussion in the living room. We spoke together for another hour. The previous sense of intimacy in our discussion was quickly regained. It was almost as if, in some way, my mistake made me easier to talk to. Although incomparable to the personal and emotional risks taken by Lynne in speaking out to a virtual stranger like myself, my error made me vulnerable, and therefore approachable, too. In any case, Lynne did not loose faith in me. We stopped taping when Lynne said she was tired and wished to finish up for the night. She agreed to meet with me again to go over the material I missed in the first hour of our discussion. We did not set a specific date for that meeting, however, but left it open. I was to call in a couple of weeks to make further arrangements.

My next meeting with Lynne took place in my apartment. Lynne chose to meet me there as it was a convenient stop-off that fit in with other errands she was doing that day. We spoke for three hours more on tape about a variety of subjects relating to her own HIV status and issues relevant to women and AIDS in general. I realize now that we never really did go over the information from our first hour of talk. There seemed to be so many more things to say.
In the end, I never transcribed the tapes from our second interview. I spoke with Lynne on tape longer than any of the other women in the study and our discussions ranged beyond the outline I followed in other sessions. I did, however, review the issues surrounding her initial diagnosis of HIV at a later date, when I began to write this chapter. I did not want to trust my memory of our first conversation. We agreed that, in keeping with how our original interview actually transpired, I would paraphrase this section of Lynne's story without direct quotes.

When I asked Lynne about the circumstances surrounding her diagnosis she told me that in the spring of 1987 she began to feel run down and tired. These feelings persisted and, after consulting her doctor, she subsequently underwent two mononucleosis tests. The tests turned out negative, but her health problems continued. Throughout the following year, she was plagued by ear and throat infections. Under the direction of several different doctors at the clinic, she took eight courses of antibiotic treatment in almost as many months. Although the doctors never seemed to question the reason for, or make any connection among, her consecutive complaints, Lynne became increasingly concerned. Both her GP and her allergist had suggested that her immune system was depressed. In the back of her mind she thought perhaps there was something really wrong with her. She suspected that something might be HIV.

Lynne had both knowledge and experience to back up her concern. Lynne and the boyfriend she had recently broken up with were both bisexual and active in the city's gay community. Lynne was involved in the distribution of the local gay newspaper, *Angles*, that has a province wide distribution. She also assisted her boyfriend in founding the first Canadian Chapter of the National Leather Association, an American-based group involved in education, and legal advocacy of consensual sex for adults, particularly sado-masochism and fetishes. Intelligent and well-informed, Lynne was already familiar with AIDS, its impact on the gay community, and its devastating effects on individuals' lives. Before her
own diagnosis, at the request of a friend she volunteered to be a "buddy" to someone hospitalized in the last stages of full-blown AIDS.

Lynne knew her boyfriend had participated in a variety of high risk activities. She also was aware of his attitude towards HIV testing. She had asked him whether he would consider taking a test. He was reluctant because he felt that, if his test turned out positive, there was no real medical treatment available to him anyway. His response was that what he did not know could not hurt him.13

Lynne felt otherwise and, once this relationship ended in December 1987, she requested an HIV test from her doctor. She was tested on the 17th of that month. She had to wait four and a half weeks for the results. Lynne says she put any thought of her test results out of her mind. The following weeks were stressful ones for her for several reasons unrelated to her HIV testing. The office where she worked burned to the ground and was relocated to a different part of town. She moved, took a holiday, and found her apartment robbed, all during this period. On January 19, 1988, Lynne's HIV test results came back. The test results were positive. Lynne says she was not really surprised.

13 The attitude that Lynne's boyfriend took is not unusual for the late 1980's. Soon after the introduction of the HIV antibody test in 1983-84, many AIDS service providers recommended that antibody testing was not generally productive, citing potential discrimination, personal distress, variability of test interpretation, and the lack of treatment as the basis for their judgment. The argument in support of testing has always been that those infected have a duty to be so informed and to take steps to ensure they do not infect others. In rebuttal to this, some AIDS service providers suggested that since people at significant risk are already encouraged to practice risk reduction, no additional benefit can be derived from testing.

Although the potential for discrimination, and personal distress are still factors to consider when being tested, in the 1990's there are now compelling reasons for those at risk to be tested. The problem of false or misleading test results has virtually been eliminated. Perhaps even more significantly, however, medical treatments are now available that have been proven useful before the appearance of noticeable symptoms. It is also now recommended that those infected prevent themselves against infection from exposure to other strains of HIV as well as against infection with sexually transmitted diseases that may accelerate the progression of HIV disease (Pinsky et al 1992: 3-5).
Having seen AIDS first hand, she was well-informed with both the physical complications and the social stigma associated with the disease. Having PWA friends and knowledge about AIDS, however, did not fully prepare Lynne for the shock of her own diagnosis and the challenge it presented to her:

I think the hardest thing about being HIV positive is facing death, and making plans for the future. A lot of people who are HIV positive say for a period of time that they can't look ahead. And I had a period of about six months like that. It was just awful. I couldn't - I think it was the summertime - and I couldn't even see the fall. I couldn't imagine where I would be living or what I would be doing.

Lynne found support and information available to her through her close association with the PWA Society. Through a strange irony, however, Lynne found that a previous experience with personal crisis proved particularly helpful in dealing with her new situation. As a young teenager Lynne had been raped. The trauma that she suffered then and her consequent journey, both personally and professionally-guided, toward healing and recovery provided her with insights into how to best take care of herself:

During the first phase, I went into heavy coping. What can I do about this? The first thing I did was set up my emotional support network, and I learned as much as I, sort of, could absorb at the time. Which, in the beginning, wasn't much. I couldn't read many articles or books. It was just too heavy, too distressing. But, I learned some basic stuff; you know, what vitamins to take, what I could do. And I did those things.
Setting up a support network she could count on was a first priority for Lynne. She went to her family and a few close friends with the news. Although divorced, Lynne's parents live in the city and were there for her when she needed them. Her mother helped Lynne to organize and educate a group of friends and family. They created an extended family support network for her, planning to provide for Lynne's various emotional and physical needs in the present, and as they may develop in the future.

Support from others has been an important life-line for Lynne, however, it also signifies great change in her relationships with those around her. Although appreciative of their concern Lynne finds, especially her parents' need for increased involvement in her life now as she approaches the age of thirty, a little sad and even oppressive:

There is a level of concern and a level of. uhh, uncertainty? I don't even know what to call it. That's quite sort of unnatural, especially with my parents. You know, I'm 29, and this should be a time in my life where my parents are around, but they're not a huge, immediate part of my life. When I was diagnosed HIV positive, somehow.. Well, I guess I needed it and also they needed it, but their parenting side kicked back into gear. And its a little hard. Its also hard because they worry. Particularly, my Father. Mom's a little bit more philosophical, more spiritual, willing to take what comes, but Dad is distressed by it. He doesn't show it, but I know its there. Its real hard sometimes to be just sort of natural and unselfconscious.

Another priority for Lynne, in her strategy for coping, was to discover what kinds of proactive health measures she could take to maintain her health. Focusing positively on what she could do for herself, rather than negatively on what could in the worst scenario happen to her, was a survival technique she had practiced before. Learning what steps she
could take personally to maintain, and even enhance, her well-being gave Lynne actual
activities to perform - taking vitamins, working out, getting proper rest - that helped her
to get through the worst of her depression. Setting up a support network and taking an
active role in her health care helped Lynne to regain confidence and control in her life.

Confidence and control are essential qualities of Lynne's ongoing well-being.
Maintaining these qualities is often difficult. Lynne finds this especially true when faced
with ongoing contacts with medical practitioners and protocols. Even though Lynne
defines herself as "not sick", she has a daunting list of medical doctors and specialists that
she sees on a regular basis. She has acquired a roster of eleven "caretakers", including her
general practitioner, an HIV specialist, a doctor who prescribes her AZT, a pharmacist, an
allergist, a dentist, a chiropractor, a massage therapist, and a counselor:

There's this huge medical event in my life just to stay sort of healthy
and normal and keep a tab on things. I don't know, maybe I'm
overreacting, but I don't think so. I've worked out this protocol with each
individual specialist or practitioner and that's how often they want to see
you. I mean, that's just the way it is. For me, its really a fortunate week
when I don't have a medical appointment on my day off, or I don't have to
take time off work, or when I don't have to, you know. When I can just
spend a whole week being me.

About nine months after her diagnosis, Lynne found herself feeling better about her
life and her possibilities. Her sense of future, that initially seemed to telescope into
nothingness, began to expand again into a farther view.

Lynne had, by this time, become adept at managing her relationships with people
around her. While she felt most at ease with those who knew of her HIV status, she was
also comfortable with those she chose not to tell, for example the majority of her co-
workers at the office. Having gained a sense of stability in her life, Lynne felt confident enough to contemplate initiating new relationships with others. The prospect of meeting new people, however, raised many questions for Lynne. One important consideration was her sexuality:

After I tested HIV positive, I went through a whole period of, you know, all the big questions - Will I ever want to be sexual again? Can I ever be sexual again? Who would ever want to be sexual with me again? Uhm, and the ethics and morals. You know, should I only get involved with other HIV positive people? You know, what should I do?

Lynne came to the conclusion that she was not willing to be celibate for the rest of her life. She had to decide how she would handle future sexual opportunities:

I made some decisions, and one of them was that before I became sexual with anybody I would tell them that I was HIV positive and we would talk about that, and talk about safe sex. So, uhm, and I think, telling friends (about being HIV positive) helped open that door because I'd had practice telling people. I also had social support and acceptance.

About a year and a half after her diagnosis, Lynne met someone she really liked through the science fiction club she belonged to. They began dating. Lynne was not sure of when to broach the subject of her HIV status with Ron, her new boyfriend. She suffered great anxiety over how to tell him and how he would react. She found herself in conflict, interested in being intimate but apprehensive of possible rejection. Finally, the moment came at a party one night at Ron's place:
We got to this kind of awkward point of, So, what are we going to do now? I finally said, Well, Ron, let's talk about dating. I like dating. Dating is good. I like dating and can we get together next week? I thought, well, I really don't want to, in the middle of a party, in this guy's house, bring up this whole issue. Its kind of big and kind of heavy. He was being insistently interested and I finally said, Well, you know, Ron, there are a few things about me that you don't know and I'd rather have some time away from the party to talk about them. I think he said, Well, if its about your HIV, Frank already told me. Because I had talked to his roommate who was my old friend and then Ron expressed interest and asked, Hey, what do you know about Lynne? and blah, blah, blah. And Frank told him, which was fine with me. Actually, it was a great weight off my shoulders, cause I was sitting there having a huge anxiety about how will I tell him? And how will he react? I was doing this weird internal dance of flirting and being interested and stuff, but at the same time really holding back because what if I got this major rejection? It was hard. So, he said that, and it was like these gates opened. And he brought it up. He said, Let's talk about it a little bit. And I said, Yeah, its true. And he said, Well, you know, I've been thinking about it and thinking about it, and what I am interested in is you, not your disease, you know? HIV must be a problem but there must be ways around it. I said, Well, yeah, there's lots of ways. He said, Well, I'm really attracted to you and let's basically try those ways around it. Anyway, we continued to see each other and continued to date. And did a lot of pretty plain talking.

Despite the intimacy of their ongoing relationship, Lynne says she did not initially share all aspects of her life with HIV with Ron:
In the early parts of our relationship, there was a lot of my internal HIV life that I didn't show him. Like, when we had been dating for six or eight weeks, about ten weeks, one day I had a date with some family and friends to sit down and talk about a living will and to do some will planning. Well, I didn't say to him, Sorry, Honey, I have to go this afternoon. I have to plan my will. It's kind of a damper on a relationship. But, I just went and I did it.

Lynne and Ron's relationship progressed. Contrary to what she might have expected before her HIV diagnosis, Ron's proposal of marriage to Lynne precipitated a crisis of emotions:

It was hard. I went through a lot of soul searching and basically, Is this right? What kind of future can I guarantee this man? Will we ever be able to, for example, get a mortgage because my income at any time could drop? There was that whole sense of, Can I hold up my end of the relationship? Ron's line is, as it has always been, It's you that I love, and I want to have whatever time I can have with you, and if we have only a couple of years, I want that much. And if we have 50 years and I am lucky enough to be sitting by your side in our matching rocking chairs, I'm going to be a fortunate male. I want what I can get.

The couple decided to become engaged to each other, but not to announce it to their family or friends for a few months, until the year anniversary of their relationship. This gave them a few months to "think and process". Lynne refers to this time as
"invaluable". Although Lynne agrees Ron didn't go into the relationship "blind", she went out of her way to expose him to some of the realities of experiencing AIDS:

I made sure a couple of times that I exposed him to what AIDS is all about. We went to see the Quilt Project, you know, and that was pretty nerving. And at one point I was organizing a memorial service for a friend that had died. I spent a lot of time at Ron's place doing that planning and stuff, and needed hugs, so he's seen the down side. (long pause) He's willing to do it, so that's fine.

As with any couple, Lynne and Ron's relationship is an evolving process. An important aspect that they have both had to adjust to is changes in the kind of physical intimacy they practice. Their sexuality is fraught with stresses which they have no choice but to confront. Ron is not HIV positive so there is always an underlying concern for his protection, the practice of safe sex involving the use of lubricants and latex barriers, including condoms and rubber gloves, precludes the type of spontaneity regular couples might take for granted:

We talked a lot about what is safe sex. And in the beginning, and till now, have practiced quite conservative safe sex. I've always said to him it's up to him to pick the limits he's safe with and I'll honor those, whatever

14 The NAMES Project is a national effort to create a hand-sewn tribute to the tens of thousands of Americans stricken by the AIDS virus. Thousands of three-by-six foot banners have been submitted to make up THE QUILT, each celebrating the life of someone who has died of AIDS. Initiated in 1987 in San Francisco, the NAMES Project first displayed THE QUILT in October 1987 in front of the United States Capital in Washington D.C. where it covered a space larger than two football fields. The Quilt has since toured throughout North America as a visible manifestation of the tremendous social impact of AIDS (Ruskin 1988). THE QUILT was displayed in the Vancouver Art Gallery in 1989.
they are. And, uhm, like one of the things we've given up is oral sex on me. And, actually, in the beginning that was my limit, which I think he learned. Now, all the clinical stuff shows that oral sex is okay, but we're still both really shy.

There's only been a few times when the mechanicalness of having to have condoms and lube and all that stuff. there's only been a couple of times when it's been an issue. I can remember once or twice when we would be getting sexual and getting out the equipment and stuff, and I remember once or twice where I just kind of shut down sexually. I think it was resentment and anger at HIV, and it was just coming out at the moment. But we are very good at talking about things, and we just cuddle and cool out a bit, and talk and sort things through.

Safe sex requires an openness and commitment not commonly anticipated or experienced between couples. It is a learned behavior. Lynne finds that knowledge, practice, experimentation, and a sense of humor, are the key to comfortable proficiency:

We're very knowledgeable. You know, use water-based (lubricant), don't use hand cream, don't use Vaseline don't use, you know, or anything like that, or massage lotion, anything that could be oil-based. So, we know how to use condoms. And I think that makes a big difference.

Quite ironically we had a condom failure the first night we spent together because we were using really old condoms and one broke. Talk about the test of a relationship! (laugh)
Lynne is fortunate to have the support of her partner, but there are many aspects of living with HIV that cannot be fully shared. Perhaps the most significant change in Lynne's life brought on by being HIV positive is her sense of reduced possibility. Lynne often feels confined by the requirements enforced on her by being HIV positive. She feels that to maintain her health she must lead a carefully controlled way of life. Concerns over proper diet, exercise, health regime, safe sex, contamination and even future care requirements, despite her best efforts, tend to drain vital aspects of choice and spontaneity from her present life:

I feel like one of the effects of HIV in my life is I have to live my life much more consciously and rigidly. You know, I have to take my vitamins, I have to exercise, I have to, you know, blah, blah blah... And I really get tired of it. I remember saying to somebody else who is HIV positive, I'm really tired of being good all the time, you know? Sometimes I'd like to go on a weekend tear. Stay up till five in the morning, seven nights in a row, if that's what I want to do. I don't think that's quite what I want to do (laugh) but, you know, it would be really nice to not have to be so consistent.

Although her health is stable now, she is apprehensive about her future. Ironically Lynne's close contact with the PWA Society, both as a peer counselor and in attending support group meetings, and her close friendship over the years with others living with HIV and AIDS, has given her vivid portraits of the difficulties that could lie ahead for her:

My fear level is high and my anxiety level is high. Every time I go to a meeting -I described it once like looking down the barrel of a loaded gun - and part of that, for me, just comes from seeing other people my age
who are sick and so on. And I feel it could be me. Or, you know, maybe it will be me. And part of it comes from the more I find out about HIV and AIDS, the more there is to fear. Information and knowledge are a tool, but realizing how many different ways I'm vulnerable, um, is hard.

Aware of the prejudice often directed at people suffering with HIV and AIDS, and having experienced uneven treatment at the hands of health care professionals, Lynne has particular concerns about dealing with doctors and hospitals. There are even more questions for Lynne as a woman, since little research has been done to document how HIV and AIDS affects women's bodies:

I'm doing okay, but if my health deteriorates I feel like, uh, I'm at the mercy of several different levels of chance. One is, who will be my health care professionals? What will, you know. What kind of care will I get in a hospital? And, what kind of medications and treatments are there and how effective are they, and what are they going to do to me in the long term or the short term? It's pretty scary to face all of that.

Lynne has concerns particular to being a women living with HIV. Issues around pregnancy and childbirth are important ones for her. Having decided that having children is not the right choice for her, she is still worried about accidental pregnancy. With the recent controversy over abortion legislation,15 Lynne is concerned about what the possible outcome might be:

15 Under the Social Credit government of Premier Bill Vander Zalm, conservative views about abortion prevailed in the province of British Columbia. At the same time federally, the existing, more liberal, legislation on the subject was being challenged by those in favor of returning abortion to the criminal code in Canada (Lee 1988:5).
What if I have an accidental pregnancy? I've made the choice that I wouldn't want to carry through with a pregnancy. I think it's a high risk for many reasons. And I also feel like I have a lot of... I've had a lot of big traumas in my life. You know, HIV is kind of just another one on the pile. And I don't need to have a sick kid, or I don't need to have a healthy kid and me be sick and feel like I can't be a mom. So I'm.. my choice is not to have a kid, but as far as I know, I'm still fertile. So what if I get pregnant and need an abortion? Am I going to have to go through the ringer and try and see 20 different doctors to get an abortion?

Despite her decision not to have children, Lynne suffers a sense of loss over how her possibilities have altered since becoming HIV positive:

The chances of my having a fairly healthy baby are probably pretty high, but I've decided that I don't want to introduce that big a variable into my life. And Ron and I have talked about it and have agreed. We can do other things other than having kids. That's O.K. But, it was a hard process. I had to go through a lot of mourning because.. Its funny, ever since I was a young teenager I had always imagined myself as a mom. Probably a single mom. And I had never ever, ever imagined myself married. It was never part of my fantasy life at all. So, here I am getting married in a few months, and I'm not going to have kids. But I.. I had to really grieve. I had always wanted to be pregnant. I had always wanted to have kids. I just had always wanted that experience. And, somebody asked me once, Have you ever thought about getting your tubes tied or something so you wouldn't have to worry about accidental pregnancy? And I said, Well, I have, but there's always that possibility of that miracle
cure. Maybe tomorrow some research team in Japan will come up with something, you know, and maybe will cure the disease or contain it and I could have kids. So, I'm not closing all my doors.

As HIV is considered to be a blood born disease, anxiety around blood and bloodshed are understandable. Lynne finds she is fearful, often beyond reason, about accidents or cuts that may put others at risk, no matter how slight, of contamination from her blood:

I still have a hyperawareness of my own blood and being really careful to keep other people away from it. If I cut myself at work or something I always bandage myself and that kind of thing. Actually, I had a milestone a couple of weeks ago. I got a paper cut at work and I didn't think about HIV till about two days later. And that, I mean, that was literally a milestone. The first couple of times I cut or injured myself after I got HIV, uh, I had a real strong emotional reaction and a real hyperawareness. I would, sort of...until the area stopped bleeding, I would be really cautious, really sensitive, about who was around. I didn't make a big issue of it, but I felt this big turmoil inside. A sense of my blood being unclean.

The sense of one's blood being unclean is not an uncommon one for person's living with HIV and AIDS. This perception takes on new significance when associated with a women's menstrual cycle. Lynne sometimes feels uncomfortable about her periods now, and, where she did not worry before, she has new concerns about sexual activity during the time of her menses. While she recognizes her fears are greater than any real risk, menstrual blood has become a symbol encompassing several negative associations:
One of the issues that's really different from men, of course, is menstruation. And so for a week to ten days every month, I have to deal actively with blood issues around sex and around... just personal cleanliness and stuff. Technically, it's not a more or less dangerous time than any other time, as far as we know. I mean, yes, there is some residual blood products or whatever around. But the theory is that my vaginal secretions and so on could contain HIV virus, anyway, so if we were using condoms and all that stuff it shouldn't be a big issue. But, psychologically, there's this big barrier. On a practical level I do what I've always done in terms of tampons, or whatever. It's more, much more of an emotional thing. If I have feelings of self-dislike or if I'm struggling internally with HIV when I have my period, a lot of that will come out and it's directed at, Oh, I hate this and I wish I could just turn it.. I wish I had an on/off switch around here. Because it represents two things. It represents, uh, possible fertility... Well, three things. Possible fertility, loss of fertility, which was a big issue for me, and the whole cleanliness and sex issue.

For Lynne, living with HIV is an up and down experience. Since she has not disclosed her status to everyone she knows, all those she works with, or even her fiancé's family, Lynne suffers the stress of concealing her HIVness in certain situations:

Well, I have good days and bad days too. And what I deal with is my mortality, and my friends mortality. And death. And I deal with it a lot. And I can't talk about it and I can't take that to work. If I have, you know, if I've got a day where I'm waiting to hear back on a blood test or something and I feel really spacey or really afraid, and I can't talk about it.
And that's really hard. Mostly it's hard because I worry that people will misconstrue. People probably don't observe me as closely as I think they do, but., uhm, I guess, I just want credit for doing as good a job as I do on those days. But it's, you know, it's hard to, it's, it's, hard to know that I do something that's difficult sometimes and I don't get credit for it.

Lynne is often frustrated because she believes that AIDS is still presumed by most people to be a male disease. With her work at the PWA Society, she has heard of women who are HIV positive but who will not come forward for counseling:

There's been a sense of isolation all along, and there's also a real strong sense of invisibility. It's a gay male disease: it bugs me when people talk about it with that slant. To me it's a human disease and it doesn't matter who you are or how you got it. What matters is that it's people and we all need to learn to deal with it. And then there's the other reality which is, if you go in an AIDS organization in North America, it's going to be probably 90% gay [male] staffed or volunteered. That's just the way it is.

Lynne would like to see more women involved in AIDS organizing efforts, especially HIV positive women, coming forward. Based on what she has seen and heard through her own work in this area, Lynne is thoughtful about the reasons why this has not happened so far:

I think I have questioned a lot of times why are women so reluctant to [make] contact and the two answers I get, one of them makes sense to me and the other doesn't. The one that doesn't make sense is, Oh, women are just really afraid and they really don't reach out. Well, I can sort of
I understand that. I mean, historically women have been very self-oppressing around trauma and anything that would make them different or "other" and I think for any woman with a partner there's a huge level of concern about their partner. If I come out, everyone will know about him. But the other argument I heard that makes more sense to me is that often women find out [about being HIV positive] when they are in a state of crisis. Maybe their husband has just been diagnosed with AIDS, or a child, or sometimes multiple people in the family, and so they are dealing with a really high level of crisis and it's very hard to reach out when you are in the midst of that. I think sometimes when you come out the other side [of crisis] and can take a bit of a breath then you're ready to reach out and say, Is there anybody else out there who is in this boat? But I think sometimes, in the moment, you just don't have the energy.

I asked Lynne whether she had thought about dying:

I did a workshop on HIV and we dealt with several issues in death. And when we did our exploring death fantasy, the thing that became clear for me is that I don't fear death. Dying itself doesn't bother me, what bothers me is the idea of being sick and being helpless. The idea of being out of control and uncomfortable and undignified is much harder to come to terms with. And I think that's one of the reasons I've worked so hard at making helpmates of my friends around some of my HIV issues because, if I come to a point where I can't do for myself through lack of energy or lack of ability, I feel I have people around me I can trust, and that's
Lynne thinks a lot about her future. She has serious practicalities on her mind. One of the conscious moves that Lynne has made since her diagnosis is to change jobs, to a place of employment that offered a union and health care benefits. Her salary is not great and Lynne anticipates health problems to confront her long before she has a chance to build up enough savings to support her through her illness. A significant impact of HIV and AIDS on people's lives is economic:

One of the ironic things about HIV is that it can be really labor intensive to be sick. (laugh) You know, trying to get a homemaker service and ensure that the homemaker will come on time or the community care nurse, or trying to find someone to install grab bars in the bathroom by the bathtub. You know, where do I buy, where can I borrow a commode? I can't afford one for the bedroom. All this type of stuff, somebody has to do it.

One of realities that many persons with AIDS must face is some kind of home health care, either from a paid nurse or a willing friend or relative. Home care is expensive and not an affordable option for everyone. Lynne is concerned that her relationship with Ron not change from what it is now to a health dependency:

Even when I'm ill I don't want Ron to become some sort of primary caregiver. I want him to be my partner still, but I don't think it would be fair to him or our relationship if he had to do all of the feeding and lifting and changing sheets. I think it's really important for my dignity and stuff for him to not have to see all of that. I mean, we'll see. It may never have to be like that, you know.
Lynne does not always have an easy relationship with her illness. Although she is generally accepting of her fate, she has moments of yearning:

I waver back and forth. There are times when I am very accepting and philosophical, you know, whatever comes, comes. And the other end of the spectrum is the fear of not having a future, not being able to finish projects, have a relationship, you know, traveling, seeing your friends grow old, and that kind of stuff.

What would I do different if I was cured tomorrow? The thing that I decided that would be different, I think, I would be a little more adventurous, sort of live a little bit on the edge.

At this point, two years after being diagnosed HIV positive, Lynne is philosophical about her condition. While she is willing to come to terms with HIV as part of her life, she is not ready to accept society's treatment of the disease or its victims. In her own life Lynne has found a place for HIV and AIDS among causes that have long activated her concern:

I'd like to see a lot more social acceptance of (HIV and AIDS), purely as a disease, like any other disease and I would be really happy if HIV were treated as matter of factly as any other disabilities. And I know that people with disabilities fight a continuing battle to be recognized and to be treated well, and be given more money. It's funny, in my lifetime I've been involved in working with [disabled] people and involved in the women's movement. Really, it's not so much different, it's just it's another struggle.
I had only spoken to Laura over the telephone before the day I took the bus out to the seaside community where she lives for our interview. Laura and her husband, Robert, of thirty-nine years live in a large, split-level home near the waterfront. Laura met me at the front door and invited me in. Cheerful and welcoming, she lead me up the stairs to the main floor. The house is colorful and cozy with the furniture and collectibles of a busy lifetime. She invited me to sit in her favorite room, a sitting room with a large skylight she had specially designed as an ideal environment for her lushly growing house plants. Relaxed and confident in the attractive surroundings of her own design, Laura gave me the impression of a person in the prime of her life. At fifty-eight, retired and already a grandmother of five, she has a full life behind her of raising a family. Laura and her husband, who is planning to retire shortly, take every opportunity to partake of their favorite activities, sailing, traveling, and meeting friends.

Laura's ability to live life to the fullest is, I learned, a response she has cultivated through a series of crisis in her own and her family's lives. After hearing Laura's story I felt new admiration for her cheery disposition. We sat together in the sun room for three hours, taking only a short break from our conversation to have a drink of juice and for Laura to take her AZT. At the conclusion of our meeting, Laura drove me to the bus station where I caught a coach back to the city.

Laura told me she first began to pay attention to news items and information about AIDS in 1984. She remembers the year because, at the same time, she was forced to retire from her job due to complications after surgery. She was interested in AIDS because it was referred to as a "gay" disease. Laura's son, Paul a professional working in the United States, is gay. She felt she should educate herself about this disease, concerned about the possibility that her son might at some time be affected.
All his life, their son has had heart trouble. As young parents, Laura and her husband had to live with the chance that their infant might not survive. Throughout his teens, with a willingness to confront the worst and make the best of the time they shared, they weathered several critical operations on their son. Once his health stabilized, Paul grew into a healthy and successful adult. Ironically, just before Christmas in 1987, he telephoned home to say that he was infected with the HIV virus. It was a great blow to the family, but one they felt they could deal with.

Determination and experience with life threatening situations have helped to shape the family's ability to deal with crisis. Laura and her husband have both had to come to terms with cancer. First, Robert was diagnosed with a cancerous polyp in his rectum in 1977. Doctors gave him less than a year to live. That was thirteen years ago. Laura herself was diagnosed with cancer in both breasts, in 1979, requiring a double mastectomy. In April 1982, she underwent reconstructive surgery. The operation took longer than expected and Laura required a transfusion of blood. It was not a success and she underwent four successive operations to try and correct the problems. The trauma of pain and suffering she experienced over the years as a result of inappropriate surgery made an immense impression on Laura. The nightmare, unfortunately, was not yet over.

Late one evening Laura received a telephone call from her general practitioner about her original breast reconstruction surgery. He had some news about the operation that had been performed on her almost six years earlier:

In, uhm, '88, January the 5th, 1988 at 9:00 PM I got a phone call. I was reading the newspaper, thinking about getting ready for bed. Phone rang, it was my doctor. He'd been in surgery that day and he was back in his office, and apparently he had had a call from [Dr. X] at Vancouver General Hospital (VGH) who was Head of Hematology. He had been contacted by the Red Cross saying that blood sent to VGH on April 14th,
'82... that some had come from a donor that had now come down with full blown AIDS. And so everybody that received blood that day, ah, their general practitioners were contacted and told that these patients must report to the Vancouver General Hospital Lab the next day for blood testing. So, that was the first time [I heard].

Needless to say, Laura found the late night call disconcerting:

I was rather upset being told that time of night, and that I had to go the next day. I thought... He could have called me in. It's no time to tell a patient at night. I mean, if he had called me in the day, I could have called AIDS Vancouver, I could have looked at things. You know, gotten myself, maybe, some help or talked to somebody. But at nine o'clock at night, who do you call or ring? I mean, after all, if I'd had it for six years, what was the rush to get there, you know? Ah, this... this is unreal! He's telling me I have to go the next day? I had company coming for lunch the next day and I had confirmed it in the afternoon. And I've got to go rushing to a lab? This didn't make sense. I mean, this was like... It was like a bad dream. And, too, my nightmare. Well, I didn't sleep too well that night. I kept reliving the surgery all over.

Her doctor had recommended going to get tested the next day, suggesting that she should get her results back by the next week. Laura remembers that he said, "I'm sure there's nothing wrong with you." She followed her doctor's advice:

I went the next day for the testing. They took my blood and I said, Will you phone me direct or my doctor on Monday?, and [the nurse] says,
You won't know for six to eight weeks. Well, six to eight weeks... at my age too! I came home and my husband had got in from work and he wanted to know what was the answer. So, when I told him, he just about went through the roof. He said, We're too old to wait for the other shoe to drop! So, he went upstairs and phoned our doctor and said, It must... is it possible to get an answer to this sooner? And, uh, the doctor said he'd contact him the next day and see what he could do. So, he phoned him the next day and he said, No, you'll have to wait for six to eight weeks.

Laura and her husband could not live with the wait. They decided to try another channel:

My husband phoned another doctor down here [in the community] that was gay. We know him. He's a very nice doctor. And asked him if he could do anything for us. So, um, I won't mention any names, but he said to have me come into his office on Friday morning and he would retake my blood and I could take it directly over to the B.C. Provincial Health Lab and he had a friend that worked there and they would watch my blood and he could get me an answer within, uh, maybe five days. Maybe ten days at the most.

And uhm, so, that was a Friday I had had it taken. Well, by the following Thursday my blood had come through: had been spotted and it came up on the ELIZA test as "probable". And they did it again on Friday and again it came up "probable". So, they did the Western Blot and it was "positive". There was no doubt about it.
Before going further, I asked Laura to tell me about her series of surgeries, beginning with the procedure in 1982 that required the transfusion of, then unrecognized, infected blood:

It was breast reconstruction which entailed a tummy tuck. And it's a messy operation where they push the flesh up under the skin from the tummy, and they cut. He cut my tummy muscles from each side. So I'm missing all stomach muscles across there [gesture]. And they get pushed up under the breast to feed the tissue that's been pushed up. Otherwise your body would absorb the tissue, so the muscles have to come up. And then they put a piece of plastic mesh across your stomach muscle to replace the muscle they have taken. Unfortunately, this was not sufficient to hold in my internal organs.

He didn't know what he was doing. They would do it for a single breast. What they would do is they'd just take the one muscle and then they'd pull the muscle together and they patch it with mesh, and you're fine. You have a nice flat tummy. But I no longer have any stomach muscles, so I find if I'm lying on my back, I can't get up.

So, anyway, he ran into trouble and instead of being a three hours surgery, it was six and a half hours. And I lost a lot of blood. It was a messed up job. I ended up with four breasts instead of two, and chunks... I had breasts under here [gesture] and, as well, up here [gesture]. And I had a big chunk under my arm here [gesture]. It was just awful.

For three months I was off work and had to walk around bent over like an ape and slowly unroll, or I could have been in trouble. I followed directions exactly right and I went back to work. Now, the surgery had been in April and this was in October. I was finding it very difficult
standing on my feet at work. I had terrible pain in my left side and it would
swell. So, my doctor sent me back to the plastic surgeon who said, Well,
there's just a tenderness there. Come back to see me in January and you
will have forgotten all about it.

Well, by January I was in worse shape. So, he says, I think you've
got a hernia. Well, that's what I told him before. He sent me to another
doctor who examined me and he got me in the hospital. They opened me
up. I had to have revised surgery. All the stitching he had put in with this
mesh was coming undone right across. So, that had to be stitched up. So,
again I was off work. It was about three months again I had to wait before
I could get back.

Get back and I'm still finding it's very difficult. This left side of
mine is really bothering me. I went back to the doctor. I guess it was
about ten months and he decides, well, he'd better put me back in the
hospital again. And he opened me up and found a hole in the mesh. He
said it was probably there when he did the revised surgery, but he hadn't
noticed it.

Finally, the last [operation] I went to Dr. [X] at UBC, who was in
on the original operation of this type. He told me it should never have been
done for a bilateral mastectomy. So, anyway, he fixed me up as best he
could. I had liposuction under here [gesture] to get rid of these [lumps]. I
asked if they could put it back the way it was before [laugh], but they
couldn't do that. They said I'd have to be very careful lifting things. I
could, you know, have a hernia if I did anything that was a strain. I quit
work. [November 1983] I couldn't stand on my feet. I couldn't do my job
properly. I thought, if I kept working I would go out of there in a box.
Laura's odyssey of operations and complications was shocking even when reviewed briefly. She says she gets "riled" just thinking about it all, even now:

[The original doctor] wanted to do that surgery. I was an experiment. A guinea pig. My doctor and the plastic surgeon at UBC both said I could have turned around and sued him. The reason I didn't was that he made me so uncomfortable and I was so tied up with having to go in for surgeries that I just felt I couldn't keep living that way: with a court case. And I mean, no amount of money was going to put me back the way I was, and I just figured I had to, uh, have a better quality of life and not dwell on something for money.

Being diagnosed HIV positive as a result of the surgery brought the horror of her experiences vividly back into her present life. She called her general practitioner to let him know she had received her HIV test results. The memory of his insensitive reaction still surprises her:

We told my doctor. My doctor was not too comfortable with HIV. What he said to me, he said, Oh, my goodness!! All those doctors that operated on you for these past six years! The poor doctors! So, that was the reaction I got. [Concern for] their safety. No compassion for me.

Not surprisingly, Laura found a new doctor. Her husband, however, still sees the same general practitioner.

Laura tells me her diagnosis inspired her to think about suing the doctor who operated on her. The statute of limitations allows a party six years from the time of an
event to take action. Laura was diagnosed in January and the statute of limitations would take effect that April:

So, I had a couple of months there that, if I hadn't found out I was HIV positive, I could have run to a lawyer and started action. But, again, finding out you are HIV positive [in 1988], they were still saying that it was a death sentence and I felt I didn't have time to waste, um, doing things like that.

Needless, to say being diagnosed HIV positive was an unexpected shock to Laura. Her husband, concerned over stigma and negative reactions, cautioned her not to tell anybody. Laura did not think she could do that:

I felt like a time bomb ready to go off. That was my first reaction. And my husband is telling me not to tell anybody, family, nothing. I said I couldn't live that way. I just screamed and shouted. I, I felt alone. Initially, I felt alone because I wasn't gay. I wasn't a male. I wasn't a drug addict. And, as I say, you felt like a time bomb. You feel... with my husband's feelings coming out that nobody should know... And then you're hearing on the radio about the houses being burned of children, you know like the hemophiliacs, the three children whose house was burned up. And they won't let these hemophiliac children into the schools. Uh, that does an awful lot to your self-esteem to make you feel, well, you've got to hide. You don't want to hide. And, uh, what's happening? It's a terrible period, but it lasted about four to six weeks: coming to terms and knowing you're not dreaming. This isn't a bad dream or a soap opera or something, this is reality and you have to deal with it in a sensible manner.
Laura's husband went and took an HIV test. After six years of unprotected sex with her, he was not infected. That, at least, was some good news. Laura telephoned her HIV positive son in New York:

When I found out for sure, I phoned my son in New York and told him that we'd just heard. The next morning, from New York, he got in touch with the Gay Men Health Crisis, GMHC, and arranged for them to send me Treatment News. He got in touch with Project Inform down in San Francisco to send me literature. He phoned AIDS Vancouver and gave them my phone number to contact me. So, he started everything for me. And then, of course, I know lots of his friends here. And he had them phone me and they were the ones who got me my doctor who was not taking any more patients. [The doctor] has [only HIV and ] AIDS patients and he wasn't taking any more. And they talked to him about me and, uh, he agreed to take me on as a patient, which I am very grateful for.

Her son arranged, via long-distance, for Laura to be put in touch with the few organizations operating in Vancouver, as well as for her to receive information from AIDS support groups in New York and San Francisco. With support information made available, and a sympathetic and experienced doctor Laura was in contact, almost from the start, with more resources than most people with HIV have the benefit of. Finding all this effortlessly, with assistance from within her own family, helped to relieve some of the confusion encountered by many in a similar situation.

Laura still suffered a period of depression, however, as a result of her diagnosis, especially when thinking of all the moments she would miss with her family.
I went through about six, four or six weeks, of sadness. My daughter had gotten pregnant, she would have loved a little girl, she's got the three boys. And uh, she'd gotten pregnant and I was so sad thinking what if I'm dead within the year and I don't see this child. And if she has a baby girl or I don't see the boys grow up. And, I mean, things that I wouldn't, no matter how well I live today, I wouldn't be there at their weddings, or see my great grandchildren, you know, and I'd get tears in my eyes.

Uhm, and as I say, at that time, I had, I guess on a talk show, I had seen Dr. Bernie Siegel and I went and bought his book [Love, Medicine and Miracles]. I bought it, highlighted it in yellow, and it was like my bible. And that put me on the right track. Got me over that. I haven't time to waste worrying what I can't or won't do. As long as I keep on doing, I could live to 104. (laugh) But it really won't matter.

Laura took no time in telling her other two children of her HIV status. They and their spouses were supportive. The decision was made not to inform her grandchildren right away. Laura was adamant, however, that they should know. She is not bitter about her disease. She feels she has much to be thankful for. Laura describes the effect of her HIV status on her family and her wish to educate her grandchildren about HIV and AIDS:

[It] brought us closer, though we were a close family. Uhm, my son-in-law is just really super. And my grandchildren just got told last year. I'd been trying to educate them, too, that not to be sorry for me or feel bad for me, just be glad that I've got this time to do things I want to do and enjoy myself and that I'm going after the brass ring and having fun. I
want them always to remember that I'd never said, Why me? It's just Now. Now's the time to start living and doing.

It's actually given me... made my life better. I take better care of myself. I rest more. I don't feel frustrated that I haven't the energy that I had before. Whereas I used to get upset because of the surgery - I couldn't do this and I couldn't do that - I haven't got time for that anymore. So, it's given me a lot of release in that way. I think I've got a better quality of life. I certainly, uh, take better care of myself. I don't deny myself of anything I want. My husband has been good. I just have to mention something I want and I've got it. I've got to be careful (laugh). I have things I really don't care whether I have or not!

But, uh, I thought the children should [know]. It used to bother me. I'd talk to my daughter and son-in-law, and my son and daughter-in-law, and I'd say, Well, I just don't want the children to see these things on TV. What are they going to think if Grandma dies of AIDS? I mean, if.. when Grandma dies of AIDS, that she was a prostitute or a drug addict? I mean, I don't think that's right. I think, you know, I wish if we could somehow let them know.

It was my daughter-in-law in [the U.S.] told my grandsons after their visit with us last August. So, it was an opportunity to discuss AIDS with them too. They are aged nine and eleven, or nine and twelve. Then my daughter got the opportunity to discuss it with my three grandsons up in [the Interior]. In November, something came up, and the opportunity just presented itself. It's nothing you can come out with bluntly, you've got to pick your times and ease it in. And the youngest boy is seven, the next one is eleven, and the next one is thirteen. And they, uhm, took it very well. They're very loving boys and they, they don't want anything to
happen to me, but they were so glad their mother had talked to them about it. And the youngest, the seven year old was, well, Grandma's going to come for Christmas isn't she? So, but they understand, I'm tired and I rest. And just suddenly sometimes I just get so tired, as if someone had given me a shot of sodium pentathol. Suddenly, I'm just absolutely exhausted and at least now they know why Grandma has to rest and they don't have to wonder. So, at least that's done. As I say, educating your family to accept it and to enjoy things [is important]. I want people to talk to me. I'm not afraid of dying and I don't want them to be afraid of me dying.

Laura felt motivated to go beyond just telling family about her experiences. In part, she felt isolated by being an HIV positive woman. AIDS in the media is so often associated with men: gays, hemophiliacs, or drug users. She had been so surprised at her own diagnosis. She wanted to educate those around her about risks of HIV for all people, and, in doing so, overcome the stereotypes that excluded her own illness:

I felt so alone. I felt a tremendous need [to speak out]. I knew I couldn't be the only woman that it had happened to. And, uh, all they talked about in the papers were prostitutes, hemophiliacs, drug addicts... All there was were these people, you'd either have gays or hemophiliacs. And, this isn't the face of it. There are other people that have it too, and they're all probably afraid. Their families won't let them come forth. They're too afraid, and it's got to come out that there's other people. And, uh, I, I thought, well, crazy, but a reason for being. I wanted to shout out, I wanted to tell people, my friends. I didn't want to be with anybody that would have a bad reaction [about me being HIV positive]. Then, I'd just as soon know [their negative response], than waste my precious time with
them. I wanted to educate my friends. If you're hiding it, then you're not you any more. And I think, and I think, too, that's a burden on your immune system. So, you're not doing your health really any good.

In talking with other HIV positive women in similar family situations as herself, Laura realizes there are consequences to speaking out that must be considered. She does not feel that she would have as much to lose, however, as younger women, who have young families to raise:

Both [another HIV positive woman] and I talked and, uhm, we're both afraid. Like, you want to get out there and say something and yet you're afraid to get too public. I mean, you can do so much amongst your friends, educating your friends and then.. I have taken.. I just took the speaker's training with PWA and I'm going to speak to small groups. So, I feel I'm doing a start. And, too, I am, I am older. I've had a good life.

Laura's urge to speak out, supported fully by her husband, is tempered by considerations for other family members. In particular, she is sensitive to the potential impact of her outspoken role on her spouse:

 When he knew how I felt and what it would do to me if I had to keep it inside, he knew that I had to [speak out], otherwise I'd be destroyed. I could not keep it within me. And he said he would back me 100%. If I had to go knock on every neighbor's door, if I felt I had to do that, well, it's not what he'd do, but he would be behind me all the way. And he is a great support.
And, too, I must remember my husband not only has a wife with HIV, he has a son with HIV. So, he's got a lot to handle. I appreciate that and I can't be totally involved with AIDS. I can't, uh, I have another life to live, too. If I didn't have any family... If I had nothing, I would throw my whole self in and be a crusader. But, as I have a life separate from it, and I'm not giving my life up because of it. My husband and family do come first.

I asked Laura if being HIV positive had effected her sexuality. She suggests the pattern of their intimacy has changed, mostly due to her insistence that they use a condom during sex:

I won't have sex without a condom. We had a terrific sex life before, and we still have good sex. My husband has a colostomy, he had cancer, he had a cancerous polyp that had spread all through his rectum. And, uh, they felt that he would never be able to have... perform again, but, he surprised me when he got home. He, uhm, I think he would have sex with no condom. He doesn't enjoy it as much with a condom. But he figures for six years we got away with it.

I don't know what he's going to be like if I'm gone. He figured, like, with this cancer, he's been in remission. They didn't give him a year to live and that's thirteen years ago. And he always felt like, you know, he was going before me. And the thought that there's a great possibility that I'm going before him... I says, Well, really, the reason you survived was because I was going to need you. So. (laugh) I think, really, if anything happened to me he would just as soon go too (laugh). And I say, Well, it's,
uh. we really can't afford both of us having this (laugh). So, we have sex, but we have sex with a condom.

Safe sex had not imposed sufficient stress or inconvenience to interrupt the good relations between Laura and her husband. The couple were surprised therefore at the response from Laura's previous general practitioner, who still treats her husband:

He goes to this doctor that I quit and he asked for [the HIV] test. He had it [again, six months after the first test] and the doctor said to him, Why do you want another test? You were negative. You're not having sex with Laura anymore are you? And my husband said, Well, of course. And he says, What!, he says, that's like playing Russian roulette! He says. I hope you're using a condom! So, anyway, you've got [an] attitude. I think we've got to educate doctors, too.

So far, Laura's health has been relatively good. She has experienced no recurrence of cancer in her system, but she has endured an ongoing series of minor complaints typical to HIV:

When we got back from Japan, that was a year ago last October, I had gotten, I had my flu shots 'cause you get flu shots when you're HIV. Uhm, but I got the flu. I was so sick. And I couldn't get over it. The cough was so bad. I was coughing and coughing. And I wasn't coughing up blood or anything, but I felt like I'd eaten ashes or something, I'd just get such a restriction there. My doctor sent me to the respirologist at St. Paul's. I had my chest x-rayed. My lungs were okay, but I had the tests for
bronchial asthma. And I have moderate bronchial asthma which is one of the things people with HIV can get.

I've had eye infections. I have a wart up in my upper eyelid I've had shaved off. They can't take it right out because you'd lose your eyelashes or something. But they've shaved it down, but it used to scratch my eye. And I've got a cyst in this eye that I can't clean up. I've had it over a year now, since a year ago January. I get it cleaned up, I go to antibiotics, both drops and cream, but it comes back again in about ten days. So, then I start the treatment all over again. So, I have an eye specialist for that. But eye infections are common for people who have HIV. I've been on AZT since October. I would have gone on it the first of September. I qualified, my T-helper cells had gotten to 300 on July 25th of '89. And when I had been diagnosed, my first ones, well, they were 320, but you couldn't have AZT until you hit the 300. So, I got, oh, I got up to 400, then I'd go back down 320, 340, 350. Anyway, as I say, in July I was at 300 so I qualified for the AZT and I was to go on it the first of September, but we had a Mediterranean cruise planned.

We'd been to Japan, every three months I was running away after having my helpers [T-4 cells] done. And so we went to the Mediterranean. Of course, I couldn't go on AZT and leave the country because you have to get, uh, the first six weeks anyway, you've got to get adjusted to it. They can't have you go out of the country and have you anemic. When you first go on AZT you must have your blood work done every week. This is so if there is a bad reaction they can adjust the dose, transfuse you or take you completely off. This is for your own safety. So, I went on it when we got back. I think was the 14th of October, and on the 16th I was at the clinic and got my first AZT, which they told me to have on an empty stomach.
Try to have it on an empty stomach. And, of course, every four hours, except I can take two at 10:30 at night and my first one is at 6:30 in the morning. And, oh, it made me so nauseous. And I... I couldn't, I was throwing up and I just... I was determined I was going to take them. And then I'd try not to throw up until at least an hour and a half because (laugh) I didn't want to get rid of the pill. So, then I found if I ate something before I had my pill, and if I eat something about an hour after, it goes fine. I seem to be able to maintain it. And sometimes I don't get sick, but other times it comes up, you know, I keep throwing up in my mouth. And it tastes so terrible. Bitter, yeah. Almost more than just, almost like bile bitter. And then that tends to make you feel kind of nauseous. So, I eat a lot of crackers.

But my weight has stabilized, I'm not losing any weight. And my blood all seems healthy. I have my helper cells done every three months. I just had them done and they went up to 440 from 300 so, actually they were 340 when I had them done in November, I think it was, or December. And [the doctor] said, Well, that they can make an error of 50, so she figured they could probably still be at 300. And then I had them done this time, it's up to 440, so the AZT and positive attitude and all that and meditation.. Uh, I'm a figure of health.

Part of Laura's personal health regime consists of taking vitamins:

I'm big on vitamins. I take vitamin A, all B's, Zinc, vitamin C. I take about 2500-3000 mgs of vitamin C. Uhm, I take potassium. I take a diuretic because I fill with water. And I take calcium and magnesium. And I eat a lot of raw vegetables and lots of fruit. I always took vitamins after,
you know, the cancer, and my husband takes them. We feel that even if you urinate them out they still may be doing some good. And we feel that maybe if we hadn't been taking vitamins that we may not have survived the cancers we got. We've always taken vitamins, but I take them in a little bit bigger doses now. Not mega doses, uhm, I've always been constipated since this surgery and I have an awful time having bowel movements because with no stomach muscles it's awfully hard. I can't push. So, I have to have a soft stool and I was drinking herb teas and all that, but I found that the increased dosage of vitamin C I'm practically normal now and with the roughage in it, it's fine. But one thing about too much vitamin C, it can give you diarrhea. Let's see, what else do I do? I like my cranberry juice and I drink lots of water. I have always drank at least 12 glasses of water a day.

In addition to the more conventional medical care and vitamin regime, Laura participates in a number of alternative health practices, including visualization therapy. Visualization therapy is an idea she gained from reading Bernie Siegal's book. It consists of an imaginative journey inside one's physical system to eliminate the disease entity in the body:

I just close my eyes and I get into my bloodstream and I go searching all over, just like you know if I'm, uh, Jack and his warriors or whatever with swords. I go all the way through all my arteries and veins chasing, (laugh), trying to kill all this enemy in me. Well, it hides, it hides. HIV is very sneaky. I was chasing macrophages, no, I was getting my macrophages, and then I found out that the HIV hides in the macrophages. So, I had to change my tactics then. So I decided I'd just visualize that I
was... Did you ever see that movie where they had this, like a submarine and they were inside the human body? Well, that's what I was! So, sometimes I'm just like that, I'm in this submarine and I'm going around looking.

Laura also carries luck charms in her purse, gathered from friends, relatives and her own travels. They are physical representations of her own and other's wishes for her continued good health. Laura does not underestimate the power of good will and positive thinking to heal:

I have, uh, a little Japanese good luck charm always in my purse. This is for health, wealth, longevity and everything else. Everything that's good. It's from Japan. And that's my wooden nickel somebody gave me, a good friend who's a chemist. That's for good luck. So, I always have these, and most of the time I wear my healing crystals. I also have a long crystal that I wear and I rub. I don't wear it everyday, but I wear it quite often about three times a week. It was from a cousin of my husband's from England who was very dear to me. She passed away and left it to me. To me, that's my healing crystal. And I also have some crystals that were my mother's that, uh, I will wear as, you know, like pearls. And, uh, oh, if my asthma seems bad I always... I put my crystals on and give them a rub. And if they weren't any healing crystals, I've made them healing crystals. So, that's all that's important. But I take anything, I take prayers, anything. Anything! I'm not against anything that'll help.

With an income of approximately $45,000 a year, and the support of family and friends, Laura appreciates that she experiences less stress than many others might with her
same illness. Another significant difference between her and the recent majority of people suffering with HIV is the way she contracted the disease. Blood and tissue products have been screened since November 1985 making the transmission of HIV via blood transfusion a rare occurrence. People who received the virus through medically assisted means, such as blood transfusions, tissue transplants or blood serum, as in the case of hemophiliacs, are often considered to be "innocent victims". Blame and stigma is more often associated with cases where the person contacted the disease though sexual contact or needle injection.

When Laura heard of a government sponsored program to compensate hemophiliacs who contracted HIV through infected serum, she wrote directly to the health minister. She objected to the formalization of a hierarchy of victims of HIV where some were favored over others:

There is a compassionate relief fund that the Federal Government is going to give to people that got the AIDS virus through blood transfusions or blood products. And it's $30,000 a year for four years, total of $120,000, tax free. The government is not accepting responsibility, you waive any right to sue the government for getting it from a blood product by accepting this money. It is strictly a compassionate relief, cause you can't get life insurance. So, I wrote a letter to Perrin Beatty [Minister of Health]. And I said I felt that everybody that contracted the HIV in those early days deserved to get [money], because they didn't.. there wasn't the education. If they wanted to change their lifestyle, they never had the opportunity to do so. I also complained about B.C. being the only province to charge for AZT. Which is another thing. They don't charge for cyclosporin if you've had a heart transplant, they don't charge for chemotherapy drugs, but they charge for AZT! I mean, you can't put it on
your extended medical insurance. It's not an approved drug. So, anyway, I complained about that in my letter too. I sent copies of the letter to the Canadian AIDS Society, and to PWA Vancouver and AIDS Vancouver and to the B.C. Health Minister and to my MP.

Laura received a telephone call from Perrin Beatty's office in response to her letter. She received an application from Beatty's office for the compassionate relief fund. The policy was not expanded, however, to include others.

Despite the screen of social protection she benefits from as a result of the medically assisted means of her HIV infection, Laura advocates treating all persons with HIV equally. She finds the stereotypes and misconceptions about the disease particularly pernicious and wishes to dispel them. In particular, she is concerned with the notion of contagion associated with HIV that can inhibit people from getting close to those who may need it most:

The labeling just tears me apart. We are all persons with HIV and we must be together as a group. It's all of us that are affected. It's not these separate groups, prostitutes, drug addicts, hemophiliacs, gays, (laugh) and grandmothers. We are all together. There's no difference. If we were blindfolded and all we could do was hear, I mean, you couldn't see what someone.. you couldn't touch them or something. That's who we are: Persons. We're human beings. We are members of the human race, whether we are black, yellow, you name it. We all bleed the same. We've got feelings and we all need loving and caring. And I think when you've

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16Laura was successful in her application for the tax-free compassionate fund. A total of $120,000 awarded in yearly installments increases Laura's yearly income to $70,000 for the next four years.
got HIV you need lots of loving and caring. You've got to think you're worthwhile. And if you just have negative things to hear, you're going to loose your self-esteem, if you had it to start with. And you've got to fight to make people realize that, this is a disease, a dreadful plague of a disease. But you can live with it and it's not [easily] contagious. You could drink out of my mug, my glass, and you're not going to get it. I mean, hemophiliac families, the wives and children aren't getting it. So, I mean, living with my husband, my grandchildren. I mean, I have my grandchildren all around me, loving, and hugging and kissing them, and maybe letting them to share my toast. And they're all fine!

After hearing her story, it struck me that HIV is not really an obstacle for Laura. Not to belittle what she has struggled with emotionally or the physical problems she has encountered as a result of her disease, it would seem that there are things in her life Laura finds more difficult to come to terms with than AIDS. One of these is dealing with the anger and resentment she feels towards the doctor who performed her original breast reconstruction surgery in 1982. Even now Laura is plagued by nightmares of her operation and finds she often requires the assistance of medication to get to sleep at night:

I don't like that doctor that did the surgery on me. I mean, I didn't like him before I found out I had HIV. I feel that he conned me and I was not happy with him. I'm even less happy with him now. I try not to let that bother me. Now, it's in my subconscious. I have control of it in the daytime, but at night, like.. your subconscious never sleeps.

Perhaps Laura has unfinished business in terms of dealing with her anger from the past, but she is doing her best not to let this interfere with her wish to get on with her
present. As of April 1992, Laura has lived for over ten years with being HIV positive. She is considered among the AIDS community to be a long term survivor. To view her situation now as successful survival or pushing the odds is a matter of interpretation. Laura is confident in her own perspective:

I have just read everything I could on [HIV and AIDS] to make myself more knowledgeable and I felt that the more I knew the less I had to be afraid of. The more you know your enemy, well, you're more at peace. I didn't want to deny the fact. I mean, I'm quite realistic that anything could happen. My status could change to full-blown AIDS. I'm positive enough that I'm not afraid and that there's things that I still want to do. I think, well, I've always had fun. I've enjoyed life. Generally, had lot's of friends. I tend to get along with people very well. And, uh, I intend to keep on doing that. I can't sit down and say, Well, why me? and waste my time. This is valuable time!
I made arrangements with Heather for when we would meet over the telephone. The day before our meeting, I took the ferry to Vancouver Island and checked into a small hotel overlooking the harbour in Victoria. Heather had requested that she meet with me at the hotel. She preferred that I did not come to her house and she felt my hotel was the most private place where we could talk. The morning was best for her, as her five year old daughter would be in day care.

At nine the following morning, I waited in the lobby to greet Heather as she came in. It was raining, but mild. All the ornamental trees along the boulevard were in full blossom. Although I had only met her once in person at a BC. Task Force meeting in Vancouver, I had no trouble recognizing her. Heather came in from the parking lot with a smile, her slim figure wrapped in a coat and her long hair wet with rain. We said our hellos. I suggested that before we go up to the room, we pick up a tray with some tea from the restaurant. We did so and soon were settled into comfortable chairs in my room. We only had a couple of hours before check-out time, so we got down to business straight away.

Heather had previously mailed me her signed consent form. I gave back to her a photocopy of the form, and then set up the tape recorder on the desk beside where we were sitting. We spoke on tape without interruption, except to top up out tea cups, until the housekeeper knocked on the door just after eleven o'clock.

Heather had much to say and seemed glad for the opportunity to talk about her experiences. She has only in the last few months begun to disclose her status to people around her, including her own family. Keeping her status secret has been a burden, but Heather is no stranger to difficult times. She has weathered considerable obstacles in her lifetime; teenage pregnancy, separation from her family, several years in a foster home, a broken marriage, and having to raise a daughter on her own. Resilient and resourceful,
she has an open, lively character and gives one the impression of being much younger than her 29 years. While there is no doubt that she is strong and competent, in her brave face I see a fragility in Heather. There is a poignancy about her story and her efforts, despite her illness, to provide the best for her infant daughter.

Heather recalls with a certain irony the first time she heard about the AIDS virus and her reaction as a parent:

I had heard about a boy having trouble going to school with AIDS in the States before I knew that I was HIV positive\textsuperscript{17}. And I thought, Oh my God! You know, 'cause I had a baby, then she was a little baby, and I thought, Oh my God, you know, how would I really react? I mean, even though your head knows, you know, intellectually you know that you cannot catch AIDS from someone by having them teach school, or the student next to you, uhm, you know, that fear is still there. That fear in your heart is still there. And you love your children so much that you would just not even take the remotest chance that they could ever contact anything like that. And so, you know, my first reaction was, Oh, God, I'm glad that my daughter isn't school age yet, cause I don't have to make that decision, cause I wouldn't want her to be in school with someone with

\textsuperscript{17} Heather is referring to the well documented troubles that the Ray family of Arcadia, Florida suffered in 1987. Townspeople attempted to bar the Ray's three HIV-positive hemophiliac children from the local public elementary school. The school board offered the boys three hours of tutoring a week if they would stay home, but the Rays felt that it was inadequate compared to the twenty-five hours a week available in regular school. The family sued the school board and won. A community group was formed, Citizens Against AIDS in Schools, and joined with a school spokesman and local parents in expressing outrage at the decision. Threats against the family increased in frequency and severity as the children returned to school under the protection of a court order. At the end of the first week that the children attended classes, the Ray family home was doused with gasoline and torched. The Rays moved out of town (Corea 1992: 116-117).
AIDS. You know, and then..(pause) Uhm, you know, now it's very different.

I asked Heather to describe to me the circumstances surrounding her diagnosis:

Uhm, I.. I never really expected to test positive, even after I was tested. Uhm, and it's even hard for me to.. I have to really think about it now. It seemed like such a long time ago. I..I was, uhm, just talking with a boyfriend one night. We..we were having a good time and giggling and laughing about old drug days and experimenting with drugs when we were teenagers and all the funny things that happened to us. You know, God aren't we glad we're over that! And, uh..uh, I mentioned that I had experimented with heroin.

We were talking about what our favorite drugs were. How we had the most fun. And I mentioned that, you know, Gee, isn't it too bad. Heroin is my favorite drug, but, of course, you know.. And he..he.. he stopped talking after and actually went white. And it scared him a lot. I had never even thought of it. That I may have contacted it. And I'm still not even sure if this is what did it.

I only tried it one or two times and, I mean, it didn't, it wasn't even prolonged. But because I wasn't into it, I used someone else's equipment. Because I wasn't into it, I just tried it for fun to see what it was like. It was great, by the way (laugh). Uhm, anyway, uhm, the person that I.. who's equipment I used, shared with lots of people. So, uh, there was a risk there. Uhm, so I went to the doctor fully expecting that nothing would be happening, 'cause I was perfectly healthy. And when it came back positive, I was really shocked.
Heather's interview with the doctor who diagnosed her was quite traumatic. She received no pre-test counseling and her doctor was terrifyingly abrupt. Heather is not bitter now. She rationalizes that in 1987, few doctor's had experience dealing with HIV and AIDS, particularly in women:

She basically said that I would be real sick within five years and, you know, just kind of sent me out and said, "Well, come back when you need help". So, I left the office believing that I had five years to live or that I'd be very sick within five years.

Uhm, too, I think I was only the second patient that she had ever seen that had tested positive. She had tested lots of people but they were fine. And, uhm, the only other man that she had seen positive, was dead. So, you know (laugh). Uhm, doctors don't have a lot of information. You know, they have very, very basic information. They don't have lots of true, face to face, contact with people, especially women. And I think she was just as freaked out as I was, 'cause she didn't know how to treat me.

The impact of the diagnosis on Heather was such that she could not come to terms with the possibility of what could happen to her in the future. She did not know what to do next. Fearing the worst for herself and afraid to confide in others, she was paralyzed into an ongoing state of shock:

I think I was in shock. I didn't know what to feel. I was really numb. I was. I was really upset but couldn't show it. I was in a. I was in a job. I was. I had to just carry on. Uhm, I'd come home at night. from the time I got home from work, to the time I went to bed, I'd drink. And
get up, and do the whole thing. I was kind of on automatic. I was really, really unhappy but didn't know what to do about it. I thought that if I told anybody I'd lose my job, I'd lose my friends, I may have to move out of the city. I imagined myself having to go underground. I got really depressed. And because I was depressed, I started getting sick, because I was depressed. I started getting yeast infections and, stupid little things, that because I was depressed, I was getting run down and I was drinking a lot.

The thought of telling people scared me. I was really frightened to tell people. And this terrible fear of rejection, like they're going to stamp everyone's forehead or we're all going to be sent to a camp. And uh.. or else spend the last two years of my life in a hospital, and it would be horrible, and what about my daughter?! You know, really blown-out-of-proportion fear because of the lack of, you know, really knowing what was happening.

In fact, the lack of information and direction Heather was given by her doctor, assisted her in forming an attitude of denial. Heather found information about AIDS from non-medical sources. She mailed away for some literature from an alternative health

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18 Heather's fear of repressive responses to being HIV positive are not unfounded. There has been much talk about harsh measures against people with HIV and AIDS. At a U.S. conference in 1985, a Harvard neurosurgeon and formerly a chief of service at Boston City Hospital, suggested quarantining persons with AIDS who persisted in "irresponsible" behavior on a state-owned island in Buzzard's Bay that was once a leper colony. In 1986 the conservative U.S. writer William F. Buckley, Jr., suggested that persons with AIDS should be tattooed on the upper arm to protect needle users, and on the buttocks to protect homosexuals (The underlying assumption to this statement is, of course, that all AIDS sufferers are male.) In 1988 in Canada a medical officer of Health proposed that quarantine should be considered in some cases (Spurgeon 1988:61). Threat is fact, however, in Cuba where people diagnosed with HIV must live in AIDS sanitariums apart from the rest of society (Rudd and Taylor 1992:178).
magazine. The article she received suggested that AIDS was probably just another form of syphilis and not really life threatening. Heather latched on to this possibility. It allowed her to put her multitude of fears aside and continue on with her life, a necessity for her as she had to make a living to support herself and her daughter.

Heather had confided in no-one. However, her doctor requested that she notify all the people she had slept with in the last ten years. As she did so, she found that none were infected. This reinforced her false hope, seeming to confirm that there was really nothing wrong with her. Eventually, however, she came to a new rationalization about how she was infected. Rather than her brief experimentation with needle use eight years previous, she thought perhaps a more recent incident was the cause. The notion of a more recent infection actually fit better with her clinical markers at the time of her diagnosis (Heather's T-4 cell count was over one thousand when she was first diagnosed, indicating a recent contact with the virus (Pinsky et al 1992:42)):

The more I learned about HIV the better I felt. In fact, I. I kinda went the other end of the pendulum about six months later. I thought,

There's nothing fucking wrong with me!! You know, like this is all been a bad joke. You know, I'm fine. It's just a little virus. I could live the rest of my life and never know it exists. And, and, uh, and I even got to the point where I was confident that the test was wrong. Because, uhm, when I finally did begin to notify people that I had sex with. I sat down and thought, for the last ten years, okay, who have I had sex with? And I had this list of about eight or nine people and called them all and said, Look, I have the AIDS virus. You need to go and get tested. Everyone was tested. Everyone came out negative. My own daughter came out negative, and I thought, Oh, it's all been a bad dream. I'll go back and get tested. It'll all be.. I'm fine. And I would have passed it [the virus] in that time,
you know. If I was positive and I had unprotected sex with all these people over the years, and one of them for like three years every night, you know, and if he's not positive then there's something wrong, right? Got another test, also came back positive. So that's why I'm thinking it may not be the drug use at all that, that... you know, I may have got it from a sex partner just before I was tested, like within the last six months before I was tested. And that would make more sense cause.. no-one has.. I've never passed it to anyone.

Heather does not focus much on the possible source of her infection. She has a theory, but she will never know for sure. There are two men that she had relations with that she was not able to locate. What is more significant to Heather is that, as far as she knows, she has not passed it on to anyone:

It's not really important to me, personally, where I got it. It doesn't really matter. You know, all I have to worry about now is.. is not spreading it to anybody else. I'm curious, but I'm not going to do any more digging to figure it out.

Heather expends considerable energy on efforts to withhold all indications of her HIV status to others. She is terrified of people's response to her. On an emotional level, rejection and isolation are her worst fears. Practically, at the time of her diagnosis, Heather was working as a live-in-nanny and feared any inkling of her status would result in her immediate expulsion from the home. It was apparent to her employer, however, that something was amiss. Finally, the woman pressed her to talk about what was obviously bothering her. Heather's first chance to reveal her problem to another person
was a disaster. Even though things worked out in the end, Heather found this incident confirmed her fears of rejection and stigmatization:

When I first found out, about a month later, I was really unhappy in my job. I was really unhappy everywhere. I hadn't told anybody and I was still keeping it inside and I just hadn't decided what I was going to do about it yet. And the lady that I worked for... uhm, after about a month of this behavior, came to see and said, Okay, Lady, you know, this is it. What the hell is going on? Uhm, finally, I broke down and I told her. She immediately went into panic, 'cause I was taking care of her children. Uhm, her and her husband went to the doctor, talked about it, the doctor assured them that unless there was blood involved that her children couldn't catch it. So, she decided to keep her children with me, which was a huge relief.

The matter did not, of course, end there. Although the woman made a promise to protect Heather's secret, Heather found that more and more people - even strangers - in her neighborhood were pointing her out as the person who "had it". After being confronted in the grocery store by someone who she did not know, but who knew about her HIV, Heather embarked upon a campaign to rectify her damaged reputation. She denied her HIV status. She told people it was a mistake, an exaggeration. She did not have the AIDS virus.

After this negative experience, Heather vowed herself to silence, but not without cost:

Very alienating. Like, it was a big stress keeping it a secret sometimes. Uhm, but when I looked at what would happen if they knew -
uhm, or what I thought would happen if they knew - keeping it secret seemed less of a stress than living with people knowing.

Heather left the home where she had been employed as a nanny and decided to open a day-care. When she found that the doctor who diagnosed her would not sign an insurance medical she needed to get licensing to operate the new business, she took determined action:

The doctor who tested me in the beginning, when I went to her for a physical examination for my day care license, she refused to sign the form that I was, uhm, physically well. I had passed the physical with flying colors. I was very healthy, uhm, but because of the HIV positive, she wouldn't sign my form. I got really pissed off. I went to another doctor. Told him I'd just moved to town. Needed a doctor. Needed a physical exam to start a job. He did the physical exam. Did a blood work thing, whatever. It all came back perfectly normal. Uhm, he signed the form and I was on my way.

So, I kept going back to him, 'cause it was really important to me that people hold me as someone who was healthy. I didn't want to be treated like someone that was sick. I do believe that people's mind set about you does make a difference. They DO affect you greatly. And it was really important to me that nobody knew. So he... I kept going back to him for anything else that I needed, which were just piddly things, you know, ear infections, whatever. Uhm, I'd bring my daughter to him. So, he became my family doctor and he didn't even know. Uhm, I always had in the back of my mind, what if I ever needed surgery? Of course I'd have
to... I'd have to tell him. You know, but I just... that never came up, so I never did.

What Heather did do, however, was to look up the AIDS Vancouver Island (AVI) organization that offered support groups for those living with HIV and AIDS. Ironically, she found this too to be an isolating experience. She was the only female, heterosexual in the group. Out of her frustration came an idea. Eventually she transformed her dissatisfaction with the services the organization had to offer into new support group for women:

I went to one of their support groups about six months after I found out. And, uhm, it was full of a bunch of gay - angry, gay men - at the time. There were two of them that were okay, and doing okay. It was just bad timing, I'd have to say. It's a wonderful group, but I felt very out of place. I was the only woman. I was the only heterosexual. I was the only one concerned about kids and that kind of thing. That's just not an issue for gay men. I was really searching out for some positive reinforcement and people that were healing and I found that, at that moment, the support group was involved in a bunch of people who weren't healing. They were angry. They were pissed off. They were pissed off they were dying. I remember one guy had slept with someone and not told anybody 'cause he was so pissed off that he had it. You know, and it was... I... I just couldn't deal with it. I couldn't... I didn't feel like I was getting any support. I feel like I went to the meetings, I poured out a whole bunch of energy into trying to support these men into living, 'cause they were so convinced they were going to die, you know, immediately. And uhm, I just... it didn't work well for me at all. And so, I put in a request to meet
other women. But where are the other women? And I didn't know about the other woman who had tested, like, two years before me. And she didn't know about me. So, uhm, I just kept squeaking about it.

I went to... a couple more meetings with the other support group and they were getting better, like those men were settling down and learning a lot and... and dealing with things. And anger certainly is a very valid, uhm, stage that you go through in dealing with this stuff. But I wasn't around to deal with their anger. Uhm, and so they were better, but it still wasn't really what I needed. I really needed women's support. And so I just kept squeaking at them. I kept saying, Look, get some women together, you know. I want... give me some other phone numbers. Give them my phone number. And it took months for us to finally connect with each other and meet with each other and it slowly kind of came together. Finally, there were three of us talking on the phone who said, Okay, we've got to get... we've all got to start talking to AVI and get something happening. We want to use their office. We want an in. And then they found Joan, who was a student willing to facilitate the group. And then the whole thing started. We had our first meeting I think in September.

Meeting other women with HIV and AIDS was a great emotional relief for Heather. Finally, she felt some sense of recognition and affirmation of her experiences. Despite differences there might be among them, they had many things in common to talk about and share. Heather made particular friends with the first other woman with HIV she had ever met:
It was great. It was like, Holy Shit! I'm not the only person in the universe! It was neat. She's very much different than me. Uhm, but we have a major thing in common. And, she's also another woman and I.. I'm feeling really connected to other women just because we're women. And it felt really good to finally meet her. And, uhm, I know that a lot of the stuff that I went through, she went through the same thing. You know, that it was sort of a.. all of a sudden all the stuff that I thought I was completely fucked up, that I thought that I was just going crazy and not handling it well, and, oh, God, was really normal and everybody went through it. And everybody, hopefully.. well, a lot of people, the survivors anyway, pop through the other side and.. and start learning about what they can do.

Despite her role as founding member of the women's support group and her contact with other HIV positive women, Heather still maintained strict secrecy about her HIV status in her everyday life. Not facing her condition also meant, not successfully confronting her fears:

I mean, looking back on it now, I put out an enormous amount of energy to have people not find out. I have cold and flu symptoms a lot. In fact, I have probably about two to three week break between either a cold or a flu happening. And that's been going on for a year. Explaining around those. Explaining, uhm.. disguising my Thursday night meetings [at AVI]. Lying about where I'm going Thursday nights. Most of the energy output was just within my own head. Worrying about losing my daycare license and what the parents would do. Worrying about my daughter, prejudices against her. Worrying about, uhm, my friends and, uhm, losing them if they were to find out, and that sort of thing. And to me, what's more
terrifying than dying, is being, separated from people and having people afraid to touch me, or hug me, or be with me, or work with me, or sleep with me.

Heather found herself in a strange position with her friends. She let everybody know that she was involved in support work at AVI, with no-one really knowing just how personally involved she was. She found herself becoming more interested in trying to educate others about HIV and AIDS. At the same time, she was trying to escape the topic entirely and live like everybody else. Trying to balance the two perspectives, and who knew about her and who didn't, was beginning to get complicated:

It's funny, because you go to a party and the subject [AIDS] comes up sometimes. They realize that you... you know a bit about it [because of her volunteer work] and its like the whole party shuts down and everybody starts talking about AIDS and asking you questions. Which is good. Which is great. I'm glad people want to know about it, but, like, I want to party! I don't want to talk about AIDS tonight. I want to have a good time with people. I.. I feel like sometimes I sort of have to either dive head first and just live it everywhere, or.. or not. It's hard to be in between. And when I'm with the people who know, uhm, it always comes up. When I'm with the people who don't know, I have to be careful that it doesn't come up. You know, I'm real conscious of what I am saying. And when I'm talking to the people who don't know, I talk in a third person kind of context. And when I talk to people I who do know, I talk about myself.

Comparing herself to all the talk she heard at parties and from her friends that don't know about her status, makes Heather angry. In her own opinion, she doesn't fit the
stereotype. According to others, as a female, heterosexual, she doesn't fit the stereotype either. She rages against this new obstacle in her life:


[Before meeting other HIV positive women] I really felt like an oddball. A freak. You know, how come? This is a gay man's disease. How come I have it, you know? What the hell am I doing with this shit, you know? I don't need this shit, you know? In comparison to a lot of the people I know who are drug users or a lot more promiscuous, I'm a good girl, You know? Sometimes, I look back and I go, God, I should have just gone wild!! I should have had all the fun I wanted, cause I caught, like, the worse thing you can get, you know. I might as well have.. You know, what was the hell of being good all that time? Sometimes I miss being able to go to Harpo's and pick up a piece of tail. (laugh) But.. Oh, well, you know. I can live without it.

Heather was getting used to feeling fatigued and regularly having flu symptoms. For any problems or infections she would go see her GP, the one who did not know she was HIV positive. Then, quite suddenly, after two years everything changed for Heather. It started out as just another cold:

I got this bad cold, uhm, I went to [the doctor] and said, Look, I've had a cold for two months it's getting worse. He said, Yes, you've got a sinus infection, and you've got this and that, and that and the other. Gave me some antibiotics and sent me home. The antibiotics didn't do anything. They made me sicker. Because the antibiotics tear down your immune system even more. Uhm, but I still thought, I'll get better. I still thought, I've just got a bad cold and I'll get better.
One morning I woke up, my lips were blue. I'd had trouble breathing all night. My lips and my fingernails were really blue. Uhm, I was having trouble staying conscious. Had to breath really hard to not pass out. Called a taxi. Went to the hospital. Checked myself in. The first, uhm. When they examined me, they took a chest x-ray first of all. A doctor who was a respiratory specialist came back. The first thing he asked me was, Have you ever used intravenous drugs? Have you ever slept with anyone with AIDS? Uhm, have you ever received blood in the last ten years? Have you ever been in an accident where you received blood? And I lied. I was so frightened. I just lied. I just said, NO. No, no, no. No, I'm perfectly healthy. Just, like, give me some pills and send me home. And when they wouldn't let me leave I started getting. They said, Look you have to stay in here. My daughter was just at daycare. I had no idea I was going to have to stay. And, uhm, I had seven kids arriving at the door Monday morning [for daycare]. And, uhm, so the shit hit the fan so to speak and everything had to come out.

Not without a struggle, however. It took two days and a close brush with death before Heather finally gave in and admitted to the respirologist who confronted her that she was HIV positive. The news set in motion a flurry of activity. "Everyone went bonkers", Heather says. The respirologist who thought he recognized her condition had seen PCP before associated with AIDS, but never in a woman. Heather had already been treated with two different courses of strong antibiotics, with no effect. Now that she was properly diagnosed with PCP, she could be properly treated\(^\text{19}\).

\(^{19}\) Pneumocystis carinii pneumonia is a lung infection from a parasite. Symptoms include fever, cough, rapid breathing and bluish skin (cyanosis). The death rate is near 100\% if untreated (Glanze 1985:579).
It was a traumatic time for Heather. On the first day she was admitted, she had to scramble to make arrangements for her daughter. It was a difficult decision for her to make, to ask other people to help her out. She did not consider calling family. They were not that close. She contacted friends from a woman's support group she belonged to that had nothing to do with AIDS.

I phoned people. I phoned my women friends, on my other women's team, and I said, Look, I really need your help. They took days off work to take my daughter. Uhm, uhm, some of them make quite a lot of money. That's a lot of money they would lose in a day to, to stay home with my kid. Uhm, I didn't have daycare arranged for her or anything. They did all that for me. Almost two weeks she bounced from friend to friend. Called me on the phone every day. Uhm, she came to see me in the hospital only once because I really looked horrid. I had tubes stuffing up my nose and in both arms and... that's kind of scary for a five year old. But I kept in contact with her. They were just wonderful.

Heather was too ill to be apprehensive anymore. She fought hard to maintain secrecy, even to the point of jeopardizing her life. Then she gave in. Fearing the worst as people around her found out, she was surprised to find that reactions to her were not negative. She found hope:

Oh, everything changed, everything you know. And it was actually a huge relief. It was like, okay, everything is going to fall apart.

Everybody going to find out. But, you know, what's really going to

20 Heather belongs to a local chapter of a women's support group called the Sterling Community. The group focuses on issues dealing with men and relationships.
happen? What's.. what's, like, really going to happen? Like, the worse thing they can do to me? They can kick me out of my job. They can kick me out of my house. They can.. but really what's going to happen? As long as they don't take my daughter away from me. That was the worse thing that I could think of happening. There are going to be some people that are going to reject me. Let them reject me. This is, you know, I can't.. I kind of can't run away from it anymore, you know. And I was very surprised. Most of the people that I told or that found out, were really supportive.

Heather found that her GP was supportive of her also. He was informed by the hospital of Heather's diagnosis and came to see her:

He was a bit freaked out. And he immediately admitted that he had no idea what to do and just referred me to other people. Which was exactly what he should have done. But also he expressed him needing to learn about it and told me that he would really like me to stay his patient and still liked to be my doctor and that this could be a way for him to learn about it.. So, I said GREAT! FAR OUT! So, I delivered this enormous package of information to his office from my house. And I don't know how much of it he'll actually read. He's kinda learning along with me.

Not feeling the pressure to hide her status from everybody marked a great change in Heather's life. She is still ambivalent about her illness, however, caught between acceptance and struggle:
I've gone back and forth. I.. like I say, there was, like, a two year period there were I thought I was really handling it. I was really healthy. You know, I was, I was functioning normally. And very few people knew and it just sort of when on like it wasn't really there. I went to my meetings and did that stuff but still felt pretty far removed from people with AIDS. Because I was doing great and na, na, na, na. And, uhm, everything was groovy, so to speak, until I got pneumonia and then the realities of having HIV hit me again, and I went through the same shit all over again. And I'm just.. I feel like I'm just pulling out of that now. I'm still struggling with colds and things but, uhm, and I'm on a drug now, pentamadine, to stop the pneumonia and I'm supposed to start AZT in a couple of weeks. So the whole thing's in my face all over again. And now I'm having to look at it all over again. Uhm, I kind of went from someone who was HIV positive and healthy and kind of still far removed from people with AIDS, to someone with AIDS. And that's.. that was a big shift.

Heather is the only one of the women in this study who has contracted an opportunistic infection that allows her to be classified as a person with AIDS. Sitting together with Heather in the quiet hotel room, hearing her story for the first time, I had to make a conscious effort not to betray the surge of grief I felt when she told me of her present health status:

My T-cell count is under that.. that of most people that have cancer and are very ill. My T-cells are very, very low. Uh, uh, when I was first tested, my cell count was in the thousands. The last cell count I had it was 150. You probably know what that means from somebody. So, around the 200 mark they start freaking out. (Laugh) Most people are quite ill
and, uhm, I'm not actually. Like, I struggle with cold things, but I did before, you know, I have all my life. So I feel like I was doing... I was really high and positive there for a while and I've gone through another dip. It's difficult to be positive when you're physically ill. And I was really, really ill.

Heather's immune system is severely compromised. I found it hard to imagine how easily the bright spirit before me could be snuffed by what to anyone else might be a trivial health problem. Heather is aware now of how information and attitude, particularly denial, contributed to her current condition:

I have to face the fact that there is really something going on. Where before it was, like, Well, I haven't given this to anybody. I'm not sick. Uhm, it was really easy to believe there was nothing happening. And there was all this evidence. I had this nice pile... thick file at home of all this stuff that says that HIV may not be nothing after all and that its probably syphilis and that, uh, supporting me and believing that everything was cool and everything was going to be fine. When in fact that's not what was happening at all. And now, you know, I come face to face with, yes, HIV is eating my immune system and I have to do something about it. That's the really dangerous thing about not telling someone you're HIV positive. In your fear of the doctors freaking out and all the other stuff, what you do is you don't have the opportunity to prevent yourself from getting [sick].

As a result of her illness Heather is required to take pentamadine treatments regularly, every two weeks, for the rest of her life. She has a new appreciation of her life
and is adamant about taking more personal action about her health. Included in that
thinking is her will to let others know not to be discouraged by ultimatums about AIDS:

Uhm, I'm getting a lot more interested in the.. in the mind-body
connection to do with AIDS. I believe a lot of people are dying..
thousands of people are dying out of the doctor telling them they will. And
I think that's really, really crucial in people's recovery and living with the
viruses is, uhm, you know, believing that they can for one thing and that
they don't necessarily have to get sick and that there's lots that they can do.
Cause it's such a helpless feeling to be terminally ill and that's how your
kind of diagnosed. As being terminally ill or something. And it's a
terrifying feeling because of the helplessness of it. And when you start to
learn that there is lots that you can do, it's really exciting.

Heather is kinder to herself, health-wise now. She finds taking care of herself to
be a positive experience. She is fighting back against the helplessness:

I stay away from negative stuff. I don't read the newspaper. I don't
watch the news. I don't listen to news reports about people with AIDS.
I'm interested, but I don't buy them as absolute truth. I know statistics are
not all that accurate. I have a naturopath and we do a vitamin regime and,
um, I try and stay away from alcohol and cigarettes. I'm not completely
successful in doing that. I don't beat myself all up when I do it. I'm
conscious about how much of those things I use. I don't eat a lot of red
meat. I try to keep my system really cleaned out. You know, I'm really
easy on myself with sleep. If I'm sleepy it doesn't matter what time of day
or night it is, I just sleep. I, you know, I don't automatically take it as a
death sentence. I keep telling myself, look, when I die is really up to me. I absolutely believe that mind has a lot more to do with it than the medical profession, especially, is willing to look at.

That some people now know she has AIDS does not mean that Heather is open with everyone she meets. She is still selective about who she tells, including her own family. Heather only in the last month made the decision to tell her family of her illness:

I still don't just, like, go out and tell people because, uhm, there are some people that it just does not work to have them know. They're too afraid themselves. I don't need that kind of energy going on around me. And I don't like people talking about me either, you know? I tell people that love me (laugh), you know, that.. that I know there's a chance that they'll understand and they'll support me anyway. But I think that's a really transforming moment. When you go from being in hiding to telling people. It was difficult to tell my family.

It was harder to tell my family than my girlfriend. Cause if my girlfriend rejected me, oh, well, I'll get another girlfriend. I can't get another father or brother, you know. Uhm, I haven't had a lot of experience with my father accepting what was happening in my life to begin with. Uhm, this has been an ongoing thing with my.. Dad was the hardest. My Dad was the hardest. My brothers and my Mom were fine. They were upset, but they educated themselves and they're, they're fine. My Dad was the hardest.

Uhm, I thought, what the hell is this guy going to do when I tell him that I have AIDS? I mean, if he didn't talk to me for eight years because I got pregnant [as a teenager], what the hell is he going to do. I.. I
fully expected him to kind of just totally draw away from me, you know. He didn't. He didn't, he did the opposite. I... I hadn't seen my Dad cry since my Mom left him when I was eight years old. He broke down and cried. He hasn't hugged me like that since I was a little girl, (laugh). Little girl, you know. And it was a major relief. Uhm, I haven't heard from them since mind you but (laugh).

All of Heather's relationships have been affected by her HIV status. Particularly important to her are her intimate relations with her boyfriend. Her efforts to maintain secrecy about her status have helped to create additional complications in her current relationship:

The man that I was lovers with when I found out, he was great. He was like, you know, we really kind of went on this journey together to find out about [HIV]. He really supported me in not buying the doctor's diagnosis. He really supported me in not reading newspapers and staying away from negative stuff..., and getting into alternative things. And he really supported me in that he wasn't afraid of me at all. In fact, I think, you know, he should have been more than he was. He wasn't afraid of me at all. It was really good for me, you know, to have someone who could make love to me and not be afraid.

The lover that I had next is the man I'm with now. And he's really difficult for me to talk about because, uhm, (pause) I..... was so convinced, at the point when I met him, that I was perfectly healthy, that I couldn't pass it, and that HIV was nothing, that I had never been sick with it, or at least nothing had been connected with it, uhm, and I was really on a roll, really positive and confident, that I didn't tell him.
Uhm, and I'm really sorry that I didn't now. Uh, I know that that was wrong of me to make that kind of decision FOR HIM. That I exposed him without him even knowing about it, which was really wrong. For him to expose himself, knowing about it, is another thing. But when he didn't even have a chance to say no...

I dated him and got to know him really well. I essentially practiced safe sex with him 99% of the time. I mean there was, like, two nights when we were drunk, home from a party. Had a great time. But 99% of the time we were practicing safe sex without him even knowing about it, anyway. When I finally did have intercourse with him on a regular basis, condoms were our birth control. But he didn't know that I was HIV positive.

It was r-e-a-l-l-y hard. I drove myself nuts, knowing that I had to tell him. You know, I kinda... in my head had, I'm either never going to tell him and he'll never know, 'cause once I've made love with him, that's it. If I haven't told him by then, you can't tell him. How do you tell someone that you have exposed them to AIDS knowingly? On purpose? That's a little... much. But I did tell him. I fully expected him to run. To be really angry. I was ready for that. Uhm. He went to his doctor. He pulled away a bit. He was concerned about me mostly because I was an absolute basket case. Uhm, he went to his doctor. He was tested. Came back negative. Of course there was a window period and he had to wait another three months to be tested. He actually waited four or five months and was tested again and was still negative. He's OK.

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21 Portions of this segment of my interview with Heather appear in Positive Women: Voices of Women Living With AIDS, Andrea Rudd and Darien Taylor, editors (1990), with Heather's permission.
Understandably, her disclosure has had a significant impact on her relationship with her boyfriend. In particular their intimate relations:

That's the most horrible thing. I mean, I would really love to sit here and tell you that things haven't really changed. But the truth is that it just totally screwed my sex life. No two ways around it. It just did. No matter how wonderful the man is. Since he's known, our sex life's gone downhill from there. It's gotten worse and worse. Since I've been sick, it's been almost nonexistent. Cause he's afraid of me. He's very wonderful about it, but he's honest. He can't say he's not afraid of me when he is. He's got three children and a business. He's got too much to take care of to risk. You know, his head and his heart disagree. So, basically what is happening with our relationship is that sex is...that sex is kinda slowly phasing out and a...and a good friendship is kinda taking over. That process has been very slow. I know that's what he's wanted for months and I haven't been able to deal with it. Because what to me looks like rejection is to him just taking care of himself. (She weeps.) You know. So that sexual relationship won't survive. There's just...there may be six months where it's real hard on him and he may get used to it or he may change his mind, but I'm not holding my breath for that. I know that he's...he's kind of. In his head he's wanted out, uh, since I got real sick. He's just wanted out. He just says, This is ridiculous. Why am I exposing myself to this?

Heather has many worries about her relationship with her boyfriend. More important to her than concerns about the outcome of this relationship, however, are her fears about her infant daughter and her daughter's future with a mother with AIDS:
Another thing that I really think about a lot is my daughter. You know, what's going to happen to me is what's going to happen to me. But what if I...what if I do die in the next three to five years? She's only five years old, you know? Uhm, I think, God, I've got to live at least ten more years because it's going to take that long before this kid's ready to be out on her own. I have to live at least... You know, when I had this kid, I made a contract. I had a contract with the universe that I would take care of her. And so, you know, I've got to live ten years because she needs me to take care of her. It's not fair for me to bring her into the world and then leave her. It's...it's not okay with me. At all. So, I think a lot about her and I think the deepest sadness around the whole thing for me is my daughter.

She knows that I'm sick, but she's only five. She cannot understand, you know? And because.. I'm very discreet about who I tell. I don't want to tell her, you know, Mommy has AIDS, because she's going to go to daycare and say, My Mommy has AIDS. You know, that's kind of... She knows that I'm sick and she knows that, uhm, there are some times when I'm too sick to be there for her. And that it's not that I don't want to be. I just don't feel good. And, uh, it's terrible, but she's getting used to it. She's, uhm.. I always had a daycare, so she never had to be in daycare. Like, that's why I created my day care. That's why I got into it. Because I didn't want to put her in daycare and go to work. Like, I didn't have a kid to pay someone else to raise her. So, I just took more kids in and eventually became licensed because I had five kids anyway. And, uhm, she's had to go to someone else's daycare so that I can sleep in the afternoon. She's still a bit too young to be unsupervised in the house for a
two or three hour block, which has been hard for her. She's in kindergarten. Next year will be better because she's in school all day.

She knows something's up. Kids are very sensitive and very intuitive. They're very open. They...she can...she can, I think, yeah, it makes her sad. She says, Mom it makes me sad when your sick... I say, Yeah, it makes me sad when I'm sick too, (laugh) but I'm doing my best, and I'll...I'll get better.". And she says, "Oh good".

Heather suffers a great sense of loss over the thought of not having more children. She finds it difficult to come to terms with perhaps not being able to fulfill all her dreams of having a family in the time she has left:

I think I've, you know, very slowly and with difficulty, decided not to have any more kids, because I'm really a kid person. I am grateful for the child I have. But there is no sense in bringing more children in when I may not survive the pregnancy, or survive even their infancy.

I wanted to complete my family. I don't like being a single parent. I wanted to get married, have a couple of more kids, buy a house and do what I wanted to do in the first place. And since I've been ill, that's kind of...ah...fallen by the wayside. It's not likely that I will have more kids now, because I'm not willing to deal with what I would have to deal with if my child were born HIV positive. I know women who are HIV positive who are having kids and its because they're willing to deal with that, and that's fine. That's great. If they're willing to deal with it, go for it. I'm not. I would not survive losing a baby. It would just absolutely tear me up.
I really want four or five kids. But I think that I'm having to just put my energy elsewhere right now. So, I'm probably NOT going to get married and I'm probably NOT going to have any more kids.

Heather is adamant about the need for support groups specifically for women. Particularly at the times when she finds her role as single parent overwhelming due to the extra demands of her illness, she knows she can reach out to find what she needs to get by:

Women need a lot of support around their families. Their kids. Uhm, what do you do with your husband? The one HIV positive woman that I know who is pregnant, her husband is HIV negative. You know, how do they cope with that? Women need to be really encouraged to contact other women, 'cause our power is really in networking. I think I would have gone bonkers by now if I didn't have the other women to talk to. Cause my potential for making good money is a lot less. I'm not able to work as hard. I'm a lot more tired. I could never do the job I used to do. I could never do day-care for ten hours a day. I physically couldn't do it. So, income is a major problem. Taking care of my daughter when I feel sick is a major problem. (laugh) It's very lonely. That's why its very important to get hold of other women and encourage each other. That we have lots of work to do, that life goes on.

That all HIV positive women may not be interested or willing to join a support group comes as no surprise to Heather. She can relate to their need to distance themselves from any reflection of what soon could be their own problems and fears. In
hindsight, Heather feels that denial is a common response that each person must grow through, as she did, to a full and open confrontation of AIDS:

I've talked to [some other HIV positive women] on the phone. They're not interested in being involved with the AIDS movement because they're still where I was, where the less they have to do about it, the less they have to think about it, the less they're effected by it. I feel like, Sooner or later its going to catch up with you! It's fine that they're healthy. Its great that they're healthy. They don't want support. You can't force someone to, you know, be part of support, but what happened to me was that I waited a long time and my immune system was really destroyed by all that time that I did not have treatment that I could have had. And I would have been better off. Because I figured, mentally, it was more harm for me to hang out with [other] people with AIDS. It's really, really depressing. If I ever met anyone [else] with AIDS I thought, Oh, my God! I was just in a depression for a week, till I completely removed myself from it again. Now I work right in the office. I'm knee deep in this stuff. I love it! It's like I can't do enough. I can't talk enough about it and I can't meet enough people. [My attitude] has completely shifted. And what shifted that is being sick and having to face it, having to tell people. Its just..like giving up fighting it. This is..this is part of my life now. I've accepted it. I'm living with it. I'm not just running away from it, pretending that it's not there.

Coming to terms with her own illness has fired in Heather a need to educate others about HIV and AIDS. She feels there is a need for more women to be visible and to speak
out about their experiences living with HIV and AIDS. She cautions that there are good reasons why more women aren't speaking out:

Fear of persecution. Someone could come and bomb your house. That sort of shit still goes on. They could hassle your kids at school. You can get fired from your job. Mostly, people lose their job. Or other people refuse to work with them and quit. Uhm, occasionally, uhm, people will get a lot of nasty treatment if they live in close quarters with people. Like if they live in communal homes, people will move out, or people will be afraid to come in their homes, and stuff like that. It seems like people's emotions have not caught up with the facts yet. Like, in your head the facts are that you can't get it from that kind of stuff, but their emotional state still plays a part in how they feel. So, I think the scariest thing for people about going public, besides from not wanting to hurt their lovers and friends, is losing their job. It makes a major career difference. (laugh) And the fear of people being prejudiced.

Heather has begun herself to participate in panel discussions about HIV and AIDS. Her intention was to take part as a resource person only and remain anonymous as an HIV positive person. At one engagement, speaking to a large group of senior high school students, she suddenly found herself taking a more active role:

There were 200 grade eleven and twelve students in a gym and I was on a kind of a panel of people. And they were allowed to ask anonymously, we'd sent out papers and they'd ask questions and stuff, and I got so moved - actually frustrated - by their lack of knowing about me that I did tell them my status when I didn't plan on doing that. And everyone
was quite blown away that I did that. Here I just told 200 people, you know. I had trouble telling someone that lived next door, but I just told 200 kids and I, (laugh) you know? But the whole thing completely shifted as soon as I said that. All of a sudden, everyone started really listening to me. And I felt a lot of power in it. Uhm, there are places when that's just not smart for me to do that, and I still have an impact [even if I don't speak]. But there's no doubt that if they know I'm HIV positive..when you're talking in your own context, from your own self, there's..there's a lot more to it than if your saying, Well, these people here, or Statistics say, or I've heard. It..it it's different. Everyone else on the panel was either a nurse or at least fifteen or seventeen years older than them, uhm, and the one man who did have AIDS was a gay man, which a lot of the kids, even if they are gay, aren't real in touch with yet and don't really identify with.

Yeah, high school. Uhm, and here I walk in, in my jeans and my tie dye t-shirt, looking pretty normal. I'm not that much older than them. It wasn't that long ago that I was in high school, you know, or high school age. And I say, Look. I got it. I wasn't doing anything weird. You can get it from sex. Uhm, and it REALLY hits home that they're at risk, when before they don't think that they're at risk. So, there's a lot of power in that.

It has to be addressed publicly and openly. It has to start being a priority, you know, in education. Uhm, everybody that walks the street has to know the risks. EVERYBODY. Everybody has to really get it: that just 'cause they're straight, just cause they're white, middle-class and they don't do drugs, whatever, doesn't mean that they won't get it.
Heather does not want to talk about dying. She dismisses the topic quickly, saying she's not ready, she has too much to do. She has to raise her daughter. Heather has a lot to say about living:

It's actually an enormous opportunity for people. I mean, when you get through all your own shit and your own fear of rejection and all the anger that you go through getting this in the first place, and, you know, and you learn about the technical stuff, understand a little bit about what's happening in your body and what you can do about it, when you get through all that stuff, really coming through the other side, is realizing what a gift it is. Because it really is. I mean, even if I only live five more years, I'm going to really live it. At least now, my priorities are straight. I really feel everything. If I want to cry, I go ahead and cry. I don't care where I am. If I want to yell and scream, I do it. I do less dishes and I go outside more. I grow more flowers and I spend more time with my daughter. Really quality time. I mean, I used to spend all day with her, but I was working. Now, when I'm with her, I'm really with her. I really listen to what she has to say. I really answer her questions. I really feel things.

You know, even if I only live five more years, I'm really living it. I'm really feeling them. And, uhm, to me, that's more valuable than living another fifty years and playing the game. You know, chasing money taking care of na, na, na, na, all the drama that goes on that just automatically stops when something like this happens. And uhm, my relationships with people now are incredible, you know. There's a connection on such a level that I never knew existed before. The only thing I could compare it with is, you know, that intimate, close magic feeling that you have moments of with your lover? That kind of stuff happens with everybody. Like, you
really feel in love, in a heart connection with everybody. Even someone who's really fucked up or misinformed, even someone who's acting in a way that's inappropriate or that you don't particularly like, you love them anyway, cause you understand. Like you really hear what they're saying. You love the person, you may not approve of what they are doing, you the love the person. Who they are. You know who the people really are, and you begin to talk to that person from a place of who they really are and you start disregarding the other stuff which used to really deeply affect me.

Now, its like it just flies over me and I start talking to who they really are.

And, uh.. I slip. There's times when I'm depressed. There's times when I'm angry. There's times when I'm sick of struggling. But what's stronger and what's under it is.. is really my deep commitment to living and what I want to do in the next five years - ten years. Who I want to be around, what I want to spend my time doing. It's.. it really changes your priorities (laugh). And, uhm, it's scary and it's like living on the edge when you tell people, uhm, but it's.. I look at it like I'm giving them an opportunity to really grow a lot. Immediately. I'm giving them an opportunity to get through their own fear to learn about something really important, cause lots of times people don't really take the time to learn about it until they know someone with it or they're affected personally somehow.

You know, I like that, that, uhm, expression "AIDS with a face". You know, nobody really pays much attention to AIDS until it has a face, until there's someone sitting in front of you, until your cousin has it, or your son's friend has it, or, uhm, someone you know dies of it. It's a different thing when you know somebody. And then you learn about it.
And the more people that I tell, the more people will learn about it. The more people that I have an opportunity touch.
I had arranged to interview Julie on the same day as I spoke to Heather. Julie also lives on Vancouver Island. She requested that I not come to her house until the afternoon. As a psychiatric nurse, Julie was used to working the night shift. Even though she isn't working now, she still maintains her late night hours. I arrived in her neighbourhood just outside the city at one PM. Her small house is set back from the street behind large bushes. As I walked up to the porch, I noticed that the blinds in the front window were drawn. I rang the doorbell and waited. After a few minutes I wondered whether Julie had forgotten our meeting. I had spoken to her on the telephone the day before I came to the Island. I had not called, however, to confirm our appointment that morning. I knocked on the door a few times. A cat appeared from the garden and stood with me on the step. Finally, the front door opened and Julie stuck her head out the door. I introduced myself. Julie told me she had been sleeping. I could see she was still in her house coat and wondered whether I should come back later. She said that it was not a problem and pushed the screen door back to let me in.

We had not met in person before. We had corresponded through the mail and spoken together on the telephone. Julie had sent me an article from a local newspaper written about her from an interview she had given the previous year\(^\text{22}\). I had an advantage then over her, as I knew something about her background and circumstances. Both from the article and in person, she struck me as strong and self-possessed, also a very private person. Julie did not, on the other hand, have an opportunity to know much about myself, except that which I had tried to convey through my written request for volunteers and our few conversations over the telephone.

\(^{22}\) Julie was interviewed by Leslie Campbell and featured in the Profile section of *Focus On Women* (April 1990, Vol. 2, No. 27) in an article entitled "Growth, Hope and AIDS".
She went about her morning routine almost as if I wasn't there. She asked me to excuse the disorder of her home, as she had only recently moved. The house looked comfortably cluttered, a large piano dominated the living room. She built a fire in the fireplace, leaving to go outside for a few minutes to cut some kindling. I felt uncomfortable that she was not prepared for my arrival. I stood about awkwardly. I tried to make conversation, following Julie to the kitchen where she prepared her morning regime of vitamin pills. I knew she had several passions: music, she sings in two choirs, playing bridge, she takes part in tournaments, and gardening. In her mid-forties and a self-described loner, Julie says she "doesn't care for chit chat" or "gatherings of more than two people". She speaks slowly and purposefully in a low voice that carries the lilt of her European origin. I watched her swallow a small dispensing cup full of vitamins, several at a time. She put the water on for tea and we went to the living room.

We sat together side by side, with a small table between us. I returned to Julie her copy of the consent form and reviewed the terms of our agreement. After setting up my tape recorder on the table, I found that with Julie's soft voice and her position in the lounging chair, I was not able to pick up her voice clearly. I suggested that, as my recorder was the small, hand held variety, she could place it in her lap as she spoke. Before doing so, she produced her own tape recorder and set it up on the table between us. I was taken aback, yet at the same time appreciative of the turn of events where the interviewer becomes interviewee as well. I told Julie that it was not necessary for her to make her own tape, as I would be supplying her with a copy of mine. She insisted, however, and I acquiesced.

I realized from her overall cautious response to me that I should have anticipated a longer interview time, to allow for us to get to know each other better. As it turned out, over an hour passed before we actually started to tape the interview. As I had already made arrangements to catch the 4 o'clock ferry back to the mainland, we had little over an hour within which to conduct the interview itself. Julie is a thoughtful person of relatively
few words. Initially, I felt that perhaps our time together had not been that successful. However, when I eventually came to transcribe the tape of our session, I was impressed again by the impact and richness of stories told in the first person.

Before we finally settled down with mugs of tea and tape recorders, Julie offered to show me a video of a news spot she had recently done on a local TV program. We went to her bedroom, where the TV was and watched the short clip sitting on the end of her king-sized waterbed. I noticed that in the article that she had sent me, in the news clip, and in our own conversations so far, she always avoided mentioning how she contracted HIV. On the news program she said that it was too personal, but qualified that it was not through either drug use or promiscuity.

When I asked Julie about the circumstances surrounding her diagnosis, she told me that she considers how she was exposed to be "confidential" information. Her reasons are that she feels how a person acquired the virus is "irrelevant, except to that person", and that she doesn't like for people to judge those infected as "innocent' or "not innocent" according to their story. I was prepared for Julie not to speak further, but she offered to describe what had occurred:

I found that I had been exposed in the fall of '85. When testing had first come out, or shortly thereafter. And, uh, I was quite shocked. How I was exposed? It was through artificial insemination. And I got a letter from the doctor that, ah, one of the donors had tested positive, that I had been exposed to him, and that I should get tested. The testing was still in its very early stages and he referred me to a Vancouver doctor. Uh, and then I found out that my GP could arrange for it, too, so I went and had it done by my GP.

I was struck by the early date of her diagnosis, and the unusual and tragic circumstances of how she contracted the disease. Only a few cases of AIDS had been reported in Canada in 1985, and I had never heard of a woman being infected in this manner.

Julie had been seeing a specialist on the mainland to try and get pregnant. She has always wanted children. A working professional who owns her own home, Julie didn't feel that being single should stand in her way. The artificial insemination was not successful. It was six months after her last insemination, and shortly after her 40th birthday, that the specialist contacted her about her potential risk from an infected donor. Julie decided to go see her GP about taking an HIV test. She had heard about AIDS, enough to know it was a matter for concern. Her doctor's response to her request surprised her:

[The doctor] tried to talk me out of it. Yeah. He said, There are social and insurance ramifications and it might be better not to know. And I said, No, way! I was almost mad at him. I just [laugh]. I wanted to know. I couldn't possibly not know. Ramifications or not. So, I took the test. There was some - quite a bit - of hope that it would turn out negative because, I was under the impression that it was not easy to, um, to get it. For women to get it. But that was probably a misconception about, uh, homosexuals. You know, because most of the men who had it at the time were homosexuals.

Julie was lead to believe that she really didn't have to worry too much about this issue. I was more of a matter of going though a routine check. She was to be rudely surprised by her test results:
Just before Christmas I found out that it was positive and I was just totally devastated. More than just devastated, I was just .. gone. I went blank. I wasn't home. I was very closed. I barely functioned at work. I was, on the one hand, steadily preoccupied, on the other hand, I was... I was totally imprisoned. I built a self-made prison. Locked myself up. [laugh] And sometimes I felt that if I went and did my gardening I would be able to get out of that. And that was a big illusion because when I got into gardening I got into the dilemma of, Am I going to plant annuals so I can see them grow this year, or am I going to plant bushes and things that take long to grow that I may never see grow old? So, you know, I was back to the same thing again. Doom and gloom. And every little symptom I had, you know, I thought, Oh, this is it.

Unprepared for the possibility of her test results coming back positive, Julie was even less prepared to deal with the consequences. She feels her doctor did little to enlighten her about what to expect from the disease. No support or resources were available. She remembers her doctor's response to her test results as follows:

Uhm, well, O.K. The results are, you are positive. That doesn't mean that you are going to have AIDS, blah, blah, blah. And when I expressed doubts and concerns, he just patted me on the back and said, You'll be alright. So, I thought, Oh, I see. I'm on my own now am I?

Julie said she felt "like a leper" and particularly isolated as a woman, because she only heard of AIDS as a man's disease. She planned to keep her HIV status a secret. One of her girlfriends remembered to ask her how her appointment went:
Well, my friend happened to find out because I was getting the results that day and it so happened that I drove her home. I wasn't going to tell her, but she remembered and she asked. And I told her. But I didn't tell anybody else. Even fairly close friends, I couldn't tell. I was even afraid that the friend that I told here wouldn't have me over again. She has children, you know, and some people are paranoid about children and AIDS and, although I realize that she is not like that, it still went through my mind. Not for a long time. I didn't tell a soul until I was feeling good. Yes. I felt contagious, you know. I wanted to disappear. And I didn't want to have anything to do with anybody because if they knew they wouldn't have anything to do with me. And here I was, a woman. Nobody I knew had AIDS or was HIV positive. And so, people.. I was probably the first that they would know and they just wouldn't have anything to do with me. That was my conclusion.

Julie sought out information about HIV and AIDS at the public library. She didn't find it all that helpful. She recalls seeing a training video about AIDS at the hospital where she works and remembers that the images of people suffering terminal stages of AIDS came back at this time to haunt her:

[The images] were of people that have wasted away, and were suffering from malnutrition, and couldn't keep anything down, and had lesions all over their body, and couldn't even stand to have the bed sheet on it, and things like that. It was just terrible. So, you wonder, am I going to end up like that? When? At least, at that time I did. Now I don't care.
Julie decided to concentrate on looking up material on subjects she was more familiar with from her own work experience. What she was looking for was strategies she could use for coming to terms with her illness emotionally:

I found it hard to understand this retrovirus business. I still don't understand it. I was more interested in finding out about dying and cancer. And cancers are close to AIDS in many ways. So, I found out more about cancer, the psychological aspects of it, not the physical aspects, and people who have survived cancer and things like that. What makes people survive.

Julie found a major turn around in her approach toward her illness came almost a year after her diagnosis through a situation that roused her anger:

My dentist said, Sorry, I can't treat you. I had told him in January that I was positive and he said, Oh, that's no problem. Hepatitis is a worse problem. It's no problem. And then in September or so he phoned me and said, We can't treat you at the office anymore, because I feel I have to tell the girls. And if I tell them then they'll refuse to treat you. They'll just freak out. And, uh, of course, that was upsetting and maddening because I thought dental hygienists and people like that, they had an association, and they were professionals, and they would be informed, and they would be, uh, under obligation to treat people, like we are, like nurses, in complete confidentiality.

I also saw a peridontist. When I went to see him next, he knew my dentist had jinxed me, and he said, I don't understand why he did that? And I said, Can you help me find another dentist, 'cause I'm a little afraid?
And he did. He found me another dentist who was not intimidated by AIDS or HIV. And then - surprise, surprise - I made a comment to the girl [at the peridontist's office] who was doing my teeth and she apparently didn't know what I was talking about, so I took it all back. And after I'd left, she promptly went and asked the peridontist what this was all about and he told her. And she walked off the job. And [the peridontist] phoned me, Sorry, I can't treat you anymore. And to this day [my dentist] has been trying to get [the peridontist to see me again.] And this peridontist said that there is no peridontist in Victoria who will treat me. However, he will treat me outside of office hours, like on Saturday morning at 8 o'clock. Which I have done once, but it's too stressful for me because it doesn't fit in with my schedule.

Julie had chosen not to reveal her status to others, except in the case of the health professionals who treated her. She thought it was only responsible for her to do so, and she expected she could depend upon their professionalism and confidentiality. The response from her dentist and peridontist seemed more than rejection, it was also betrayal. Julie felt that these health professionals, no less than herself in her professional role as a nurse, had a code of conduct they were expected to uphold. Her case should not be an exception. It was no comfort to her that the peridontist himself said he had no problem with the situation, since he could not bring himself to inform or educate his staff.

The outrage Julie felt shifted her thinking, reminding her that, in spite of her illness, she was still a person and she still had rights. She went so far as to contact a lawyer, and considered taking legal action. Her invigorated spirit was put to its best use in a new aggressive attitude towards her illness. Julie said she decided to fight back. She came across a book that seemed just right for her because it gave guidelines for how she could
go about doing just that. The book, *The Immune Power Diet*, gave recommendations for vitamin doses that could help to maintain one's immune system:

So, whereas before I'd heard about vitamin this being good for the immune system and this being good, like zinc, that was all fine, but how much zinc, you know? How much was enough? 10 milligrams? 70 milligrams? What? So, this book gave me guidelines about how to combine it, and what goes and all that. And I made it into a bit of a.. a project. A positive project to figure out the combinations of things. Like you get a multimineral pill which has a lot of everything, but it might not have enough of this, but it might have too much of that. So, I would figure out ways to make it right, that would be the cheapest and the easiest. And I really enjoyed doing that, you know. I was really involved in that. Oh, now I've got something to put my teeth into! And I also felt that I wasn't just waiting for "IT" to get to me, I was out to get "IT". That was the big turn-around. It didn't really matter if the vitamins helped, it was my psychological turn-around that was important.

Once Julie felt she was getting in control of herself again, she felt confident enough to handle the risk of sharing the knowledge of her illness with others:

- It was after Christmas, so that was over a year, that I started telling some of my friends. Like, the ones in Vancouver. I had seen them, but I hadn't told them. And this time I told them. But now I could be positive. Its much easier to tell somebody when you can tell it in a positive way, rather than, Oh, dear!, you know, I'm just devastated! You can't talk to people when you feel like that. Then you feel somewhat excited and you've
got a grip on things, then you can say, Well, I've been through this mess, but I've come out of it okay. And I've got a bit of news (laugh)... some news to tell you. They were okay. They took it, uh, well, not lightly, but they didn't make a big deal of it either. It spurred their interest in HIV and AIDS.

As it had affected other aspects of her life, Julie found that being HIV positive had an affect on her sexuality. Although she was not in an intimate relationship with anyone at the time of her diagnosis, she had not been closed to such a possibility. After her diagnosis she found herself avoiding men:

Well, it was a (laugh) sub-conscious thing. Like, uh, I wasn't ready to deal with that issue - having to deal with HIV and the possibility of rejection - within a relationship. I didn't know what to do with it. So, I forgot about men and my body sort of did it for me. It protected me. And, you know, my sex urge just went out the window. Uhm, now I feel that I could handle a man. A relationship.

I asked Julie whether she made contact with the local support group for persons with AIDS, AID Vancouver Island. She said she found out about the organization shortly after her diagnosis, but was initially cautious about contacting them. She wondered whether the group would be welcoming to her as a woman:

I first called them a month or so after I had found out my status. And that was with a lot of fear and trepidation 'cause I didn't know who was AIDS Vancouver Island. And it was at the time, five years ago, when it was sort of a one man office and they had a line open evenings between
seven and nine. And not all evenings either. So, I phoned and I asked, Who are you? You know, who is AVI? And I didn't quite like the answer. There was a bit of an emphasis on gay men. And I thought (sigh), I'm not a gay man. And the person I talked to really wasn't listening to me as much as he wanted to impart information. After this first question, I just wanted him to listen and he didn't so I thought, scratch it. I probably got this from a gay person who wasn't being honest and put me at risk. I don't want to get involved with a bunch of gay people. That's where I was at then.

And then later on, when I got into the vitamin business (laugh) I made contact again with AVI and I talked with someone who was more appropriate, I guess. And they were just starting up a support group and was I interested in joining. And I said, Yeah. Gay men or no gay men, that's fine. I was over that. I just wanted to know other people who had the same problem. Who were living with the same thing. And I did, and it was a very good group. All the people were very positive and responsible. And neat people. And the group was very inspiring. It helped me find more things that I could do for myself.

Julie practices a personalized health regime that includes attention to her diet, vitamins pills, surrounding herself with natural, rather than man-made, materials, consultations with a naturopath and a magnetic healer, and attempting to cut down on smoking:

Well, over the years I've done the vitamins and I've persisted with them. I've been searching for the right kind of diet. I'm not sure that I've found it, but I've been searching (laugh). I do my best. Uhm. From way back when I decided not to wear anything that is not cotton. At least not
next to my body. Or sleep on anything that is not natural. I've got a waterbed, but I have I don't know how many layers of woolen blankets underneath and a cotton thing. And when I remember, I turn the heater off before I go to bed, so I don't have the magnetic field.

Vitamins. Diet. Uhm, no alcohol, no. Well, almost no sugar. At least I avoid it. No meat or animal protein, except under duress. [Smoking?] Uhm. I've been struggling with that. I've quit about three times in the last three years or so. And it hasn't lasted. I quit a month ago and it didn't last. I was okay for about a week and then I didn't manage. But the times before I've quit for longer. So, I'll keep on plugging at it. It's my only vice.

Ah, I started. I got a juicer and I started, when I had time and when I was so inclined, I started making vegetable juice. And I really felt psychologically that that was of benefit. To have the raw, fresh juice. When, you know, I can't eat half a pound of cabbage, or a half a pound of carrots or even a combination. I mean, its just too much. But in juice you can eat a lot. Mind you, you don't get the fibre, but you get the enzymes and all the other goodies. So, that has been a positive thing I did for myself.

Julie enjoyed the health regime she took on. She found it empowering. Her doctor had suggested that she should check back with him on a regular basis every few months to follow up on the progress of her disease. Julie decided not to. She says she thought, Why? There's nothing they can do for me anyways, so why focus on it? Instead she sought out a naturopath:
I didn't know what they were at first, so I finally got over that hurdle and went to see one. And I liked what they had to say and what they were doing. They did not throw up their arms about HIV. So that was nice. They helped me find things to help myself, you know, diet-wise and vitamin-wise. And other things I didn't do, like take a walk every day. (laugh) I do my garden every day.

She did, however, go to Vancouver to see a blood specialist at St. Paul's Hospital at her lawyer's recommendation. She needed to have the standard blood work up done so that the doctors could follow the impact of HIV on her system:

Ah, I went to see a doctor in Vancouver who is connected with St. Paul's to get the tests done for T-4 cell count. You can't get it done in Victoria. And that's over a year ago and my T-4 cells were beautiful! They were just wonderful. And they said I was good for another year. So, I was all happy and I thought well, maybe I won't have to get AIDS. I can just go on being HIV positive. I made plans for moving. I moved here in October. I had lived in Sydney for 18 years and owned my own house.

The doctor's report on Julie's T-4 cell count seemed very encouraging to Julie. Her T-4 cell count was 1,090. She felt under control. She felt she was adjusting well to her new situation and, perhaps there would be no problems for her. She moved her residence, bringing with her all the shrubbery she could transport as well as a supply of special compost material she had laboured to create. She had chosen the new property because it had a large yard, and it was closer to work, her clubs and the support group. It was also easier on her financially because of the smaller mortgage, shorter commute to work and less wear on the car. During this time she maintained a busy evening-shift work
schedule at the hospital and continued to take part in her favorite extra curricular activities outside of gardening: choir and bridge. She was settled in her new home by Christmas. Just after Christmas she flew to Reno, Nevada to attend a bridge tournament:

On the way, I was very tired. Even in the airport. I'd brought a book and I was going to read it, because I'm not someone who can do nothing, even at an airport. So, I brought a book, but I couldn't even read the book! I just.. Mind you, I hadn't had a very good sleep, I just closed my eyes. I couldn't sleep either. But all I could do was just sit there with my eyes closed. And the same on the plane. I was just soo tired. Then I thought, Well, that's probably the move and the winter blues. Usually, in the winter I crash. I feel somewhat lethargic, whatever. It's the quiet after the storm. (laugh) I'd had my excitement and now I'd have to crash. And I went to the bridge tournament and, uh, inbetween sessions - and the sessions started at 1:00 PM until about 4:30 or 5:00 and start again at about 8:00 til 11:00 or 12:00 - in-between the sessions you usually go and have dinner, but I went and had a sleep. I felt I needed it. I never thought anything of it either.

And then I came home after a week and I had to go back to work right the next day and I was sooo wiped. After another day and I was sooo wiped, I took two days off, just because I was so wiped. And that's unusual because I've never taken sick days off just because I'm tired. But I still didn't think anything of it. And I went off in another week or two to the Vancouver bridge tournament, which I hadn't realized was following so closely after Reno, or I wouldn't have booked Reno. I couldn't not go to Vancouver because it's so close by. And by that time I had learned to be easier on myself and I didn't book myself all the games. I, uh.. When there
was an opportunity, I would play only in the evening. In the afternoon I
went to bed.

While she was over in Vancouver, Julie decided to contact the blood specialist at
St. Paul's. She had been told to come back in a year. She was slightly overdue for her
appointment then, as a year had passed as of the previous November:

So I went back to him. And he did my T-4 count. That was after,
just after the tournament and I hadn't slept well. I think I'd had coffee the
day before and I had been awake til all hours of the morning. I hadn't had a
good sleep. And I was wiped anyways. He examined me, and then he
said, Well, your T-4 count [has] dropped a lot from last time and you're on
the verge of qualifying for AZT and I think that if I ask [the doctor who
reviews the qualifications for AZT] about it he'll approve it 'cause its such a
drop. [Her T-4 count was 510 or 520. By this time a count of 500
qualifies a person for AZT in British Columbia.] And I hardly heard what
he was saying. I was thinking, I don't understand why there has been a
drop! I've been taking care of myself. I've been so good to myself. Why
has this gone so low!? And, uh, (sigh) I didn't quite understand why he
was talking about AZT. And he explained about AZT, that, you know, it
helps more when you go on it early and blah, blah, blah. And he drew me
little graphs. And, you know, why is my count so low? Why don't you
shut up and tell me that? Right?

Julie was plunged into crisis in an instant. She remembers little of what the doctor
said to her after his initial pronouncement. She was tired and in shock, with a long trip
ahead of her back to the Island. She got to the ferry terminal on time, but did not make
the ferry she planned because there was too many cars for the boat. By the time she was back home she had planned her next moves:

I had to wait two hours and I just laid down in my car and went to sleep. I've never done that! Then I got home and I went to sleep, never mind anything else. But it was clear in my mind what I wanted to do. I wanted to first of all see my naturopath, and second, but not least, go see my doctor and get some time off work, because I realized I was wiped and now that my T-cell count was low I needed to get that back up again. And I needed what little energy I had to get that back up again.

Julie went to her naturopath for advice, then went to see her GP. She informed him of her new lower blood count and that she was suffering from chronic fatigue. He wrote a letter to the head nurse of the hospital where she worked to allow her time off until further notice. Concerned about the report she had received from the specialist in Vancouver, she had some questions for her doctor:

Trying to understand this all, I asked him, Is this the beginning of AIDS? And he said, Yes, I'm afraid so, and he had tears in his eyes. You have about three years to live, or you might go very quickly. And I cried. And I thought, What about my cat? What about my house? I can't handle the garden. Its, you know.. I'm too wiped to do anything. And I'm not going to have the money to hire somebody. Uhm, I'm going to have to sell the house! And those were my first concerns.
Julie's world again imploded with her doctor's limiting view of her future. The shift from HIV to AIDS indicated a terrifying change for Julie, including her inability to continue working. At another time of her life, not being able to continue working would have been more traumatic for Julie. Now, however, she was relieved. Work had been stressful and now she would have time to devote to other activities, such as taking care of her own health.

Facing her own mortality, Julie's thoughts turned to her mother who had died young at 49 years. She had sometimes feared that somehow the same fate might befall her as well. It was only in the last year that she felt she understood what had happened to her mother, and realized how different their situations were. Having just liberated herself from this fear, ironically she found herself thrown back into the possibility that she too might die just before her 50th birthday. In despair she turned to her friend, the person she had first confided in about her status. Her friend was supportive and comforting. She recommended Julie read Bernie Seigal's book, *Love, Medicine and Miracles*. Julie found it very inspiring, as it reviews the stories of patients that have achieved peace and significant control over their health problems through spiritual, self-healing techniques. Included in the book is an open letter from a patient to her doctor that is meant to assist a patient maintain control over her health and foster a meaningful doctor-patient relationship.

The book helped Julie to see her own doctor in a new light and to see that there were different possibilities for how they could work together in the best interests of her health. She went to see him armed with Siegal's book:

I read to him the open letter to physicians that's in the book. I read him the relevant parts like, Don't tell me when to die, that's up to me, and, uh, if I seek alternative medicine, don't desert me, I may need your medicine mostly when I'm the sickest, and, continue to teach me your
beliefs, I may convert at sometime when I need it, and that sort of thing. And, uh, he really took it very well. And he said, I must get that book! And while I was reading something else, he wrote down the details of the book. So, I thought I'd done well in educating him. And that, I felt, was the beginning of my role in education.

I also asked him, if my fatigue could have been caused by anything else other than AIDS, before I pulled the alarm. And he said no. So, then I decided to call a meeting at work, which is rather unusual, for a revelation of your condition.

Now on long term disability from work and having to come to terms with the possibility of a limited future, Julie felt she would like to go public with her personal experience with HIV. She had been surprised by the show of support - flowers, cards and calls - from her colleagues at work since she had retired. No reason had been given for her absence and she was pleased to find that people did not pry. She decided she wanted them to know:

I called a meeting at work. Even the head nurse didn't know what was going on. There were three people at work who knew and they were absolutely trustworthy. They didn't leak anything. Other colleagues knew who they were and tried to pump them, but it didn't work. Even the head nurse tried to rake one of them over the coals about what was the matter with Julie, but she stood up to it very well. (laugh) So, it was a very well guarded secret. The ones who knew I was HIV positive, they were on the phone the first time I was off. The first DAY I was off sick. We are concerned. Anyway, then I had my what you might call my day in court at work. I was really looking forward to it.
I presented it, I think, fairly well. There were 20 people there and you could hear a pin drop in that room for a half an hour. I had first told them that I understood that they were apprehensive about what I might say and that this was an unusual way of communicating, but that it was the only, to me, appropriate way to tell them what was going on, because I didn't want it going through the grapevine. I didn't want to put it up on the board. It had to be face to face with as many as possible. And I told them I would give them the bad news first, which I did. I said, I have AIDS. And I said, if you get over your shock for the moment, I will give you some background. And I did. I told them what I'd been through in the last five years, up until the present time. And then I ended up on a positive note. And I didn't tell them how I got it. But I made a bit of a joke about it. And that was spontaneous. I said, I didn't get it through drugs or promiscuity, you can probably tell by knowing me. And then I sort of chuckled and said, And I didn't even get it in anybody's bed, and I'm getting to old to do it anywhere else. (laugh) Nobody laughed but me! So, you know, I was very free, but they weren't.

Julie enjoyed the drama of her presentation. She knew she was not what most people would visualize when trying to picture a person with AIDS. She hoped the news would shock them. She had reasons for speaking out in her workplace:

For me it was important, because we have had HIV patients [in the hospital]. We've AIDS patients, HIV patients and, uh, the staff labels them. I mean physically labels them. They put yellow stickers on everything [to signal the need for universal precautions] And also, when
someone is being tested for HIV or is a just a male homosexual, they put yellow stickers on everything.

We had one person who was HIV - only HIV positive - and they gave her a private room, which was understandable because she was a transsexual, but they also had her eat out of paper things. They haven't made anybody else do that and I thought that was so weird. And she was the last one who needed that because she was not only coping with the weirdness of being transsexual, plus having HIV, she also had, uh, cerebral palsy. So, she was really, uh, someone who was unusual and is being treated differently, and here she was being treated differently again. And I wanted to make staff aware that AIDS is not just a problem of the other side of the desk, it's right in their midst. Here I am, you know. In other words, not to look at the target groups only, but maybe its the 55 year old widow who had a trip to Hawaii and a little fling with the wrong person. Who knows, you know? Anybody can get it. You never know. And, you know, that's my.. that's my lesson. Anybody can get it.

Julie also would like others to realize some of the financial complications and hardships that commonly occur with the onset of HIV and AIDS. Since going on long-term disability from work, Julie receives only a portion of her regular $30,000. a year salary. She still has a mortgage to pay and added expenses of aspects of her health regime not covered by health care. She has a message to the health ministries that have, to date, been focusing their funding on campaigns to prevent the spread of HIV:

Not just women, but anyone who is in this position with AIDS, has AIDS or is close to having AIDS, their money goes down. I'm on long term disability. I'll have less money and I don't know if I can keep this
house. [Another woman with HIV] went from having her own business to being on social assistance. This is also true for men. [You] go on UIC or welfare, so that's a financial hardship, but on top of that is what you pay for medical things that are not covered Medicare, like the vitamins, the naturopath, the alternative treatments. And it really adds up. Some months I pay over $300. that is non-refundable. And that's a big concern. If [government] is going to distribute money, I think they should distribute it to the people who need it most, rather than for publicity or awareness. A lot of money has been spent on education and awareness, but allot of money needs to be spent on people who are actually having the problems.

Julie feels she is a good spokesperson for AIDS, just because she is what she defines as "an unlikely suspect". Speaking out about her experiences helps her to cope with her recent diagnosis of AIDS. She has a new purpose. She says that even though she suffered a brief depression, she knew she would come through it. She said she came out of it feeling "very positive and very challenged". She refers to it as "the beginning of my emergence". Not only did Julie give up all efforts to hide her AIDS status, she made herself available to speak out publicly about it. In this way, this very private person found she could retain a measure of anonymity through public speaking, and relieve herself of the stress of dealing directly with the feelings of others towards her as they worked out their responses. From a safe distance she can gain the sense of support and approval she needs from her audience:

I did not, at that point, care who knew that I had AIDS. Actually, that same day somebody said to me, after I had said what I was going to say at work, she said, Would you like an interview? Would you like to be in [Focus On Women, a local paper]? And I said, Sure! And she gave the
editor a call and arranged it. And that was fine. I was looking forward to
that, too.

In a way it takes the burden off me to tell people. Its another way
of telling people, you know? Like, I can't tell everybody individually and
then have to take care of their feelings and their reactions. (laugh) And this
way I can reach a whole bunch of people. Plus, I can reach people who
don't know me, but do need to know that AIDS is right here and that it is a
reality. And it can hit women, and it can hit anybody. It's really my feeling
that I have to get that message across and I'm a good one to do it.

Since she was first diagnosed HIV positive, Julie says she has thought about dying.
At that time it was with "trepidation", but she has since come to think of death without
fear, even playfully:

When I was first HIV positive, I thought, Well, I guess that means I
could die sooner than most. So, I started reading more about dying. And I
find wonderful books about dying. You know, most books you read about
dying are really very beautiful. And this one was about a 20-some year old
who had melanoma and her parents had written a book about what had
happened and the progression. And the girl hadn't been accepting of her
illness or death, but she came around to it just in time (laugh) so to speak..
And it was very beautiful. And I said, Wow, this is fantastic! I thought
about what I want for a service and what I want to do with my body. And
I've had fun with it.

Julie's fantasies about her death and burial are uniquely hers, reflecting her
concerns and interests:
I would like my body to be unstuffed and organic (laugh). And buried, preferably, without a casket, and preferably in a spot where the worms will be able to transport the goodies to somebody's organic garden nearby. Most people freak out when they think of worms on your body. I've listened to the [Handel's] Messiah many times and I've participated in it and there's this passage "and though worms destroy his body" and, uh, well, that's the natural thing to do really. And I would like to be in the earth with the worms and anybody else who can use me, you know? I want to be in the earth. I want to be buried. And give off fumes and destroy the ozone. (laugh) I want to be environmentally sound. Its probably going to be hard to find a place that won't stuff you up with poisons and that, uh, that, uh, has an organic garden nearby that the worms can migrate to. (laugh) And I haven't researched that. Its sort of a fancy. I'll have to leave it to [the executor of her estate] when the time comes. Or maybe I'll look into it myself.

And then the memorial service. If I have time, like, its a little premature and I haven't been inspired yet, but what I would like to do is make a tape for the memorial service that's kind of funny. Like, Hi! Nobody regrets not being here as much as I do. (laugh) But, however, who knows, maybe I'm here after all. And, uh, you know, be sort of, be fairly light and yet very, uhm, very inspiring at the same time. I want to be inspiring in teaching about this.

Julie is soon approaching a decade of living with HIV. In two years she will qualify to be described as a long-term survivor. Her life has been transformed in many ways as a result of her illness. She has gone from being a very private person to one
actively seeking a public role. Julie has come to a rationalization about her experiences that is positive and allows her a meaningful future:

    We all have to deal with, um, whatever comes up. For me, part of this is the finality of not having children, which is very sad. And, uh, that might of happened even without having AIDS or being HIV positive. You know, I might have had to face death. What I thought at one point is, you know, some people would think it was very unfair or be very angry. I went in to get a baby and I came out with AIDS. Basically, that's what happened. There must be a reason for that. You know, other than the obvious ones. There's a cosmic reason for it. I thought, Well, having a child and raising a child is a great challenge, but I needed a bigger challenge. And that felt right. That felt nourishing.
CHAPTER THREE
PERSONAL AND SOCIAL IDENTITIES:
MANAGING OR BEING MANAGED?

Illness is a transformative experience, altering the borderlines of the self from what they were before, and limiting and impairing one's sense of wholeness (Kaufman 1988:345). In the cases of the women described here, every aspect of their lives has been altered by their diagnosis of being HIV positive. The unpredictability of AIDS and its unique manifestations in each person adds an additional dimension of uncertainty and change to lives already seriously disrupted. The women have no clear expectation of how their illness will affect their lives in the future. They have many fears. Illness shapes their experience even when they are asymptomatic, as any change in the self is scrutinized as a potential indication of the onset of their disease. Being HIV positive means moving beyond the norms of their previous experience. The women appear to live in the same world as they always have and yet their perceptions are radically changed. To them it is a different world with different values. It is not easy to share this, even with sympathetic family and supporters. Being HIV positive is an isolating and alienating experience.

Over time the women have learned to make this experience livable by carefully managing their personal and social identities. They pass as normal in certain situations and with certain people, and for the other times carefully choose who they tell about their HIV status. Pretending to be what you are not is a strain, yet all the women seem to value the times that they try to put aside their illness for a while. On the other hand, to feel comfortable with who they are now and their HIVness is, for all of them, an important, maturing necessity. It is also an ongoing process.

Being able to come to terms with the new qualities of alienation and vulnerability in their lives is not a possibility for everyone. The women featured here have, each in their
own way, been able to take advantage of various aspects of their transformative experience through illness. If illness has set them outside of the norms they are familiar with, they have found it has also provided them with opportunities to forge new priorities and values for themselves. As a result of what medicine cannot offer them in the way of direction or cure, and through their own actions to control their health and well being, the borderlines of medical care and intervention are also challenged and transformed.

Personal Identities: Managing

Being diagnosed HIV positive was not an expectation that any of the five women in this study had imagined for themselves. All of them, even Lynne and Heather who requested HIV tests from their doctors, blundered into their diagnoses with no preparation. At the time none of the women were suffering symptoms that they might associate with AIDS, yet suddenly they found themselves defined as terminally ill. All of them remember the moment of their diagnosis vividly as the instance marking their lives before and after AIDS entered their lives. Accompanying their change in identity from self to HIV self came a host of imposed labels - sick, contaminated, contagious, diseased, victim - that they needed somehow to address. What followed for each woman was a private journey of self-informing to discover what new self identity each would chose: what to accept and what to reject of the labels imposed upon them by their illness and the perceptions around them. They found themselves in a dilemma. One could not simultaneously define herself as a sufferer or victim, and a worker, mother, daughter, caregiver, parent or lover. Finding room for a variety of selves, trying to restrain the illness-self from taking over all the roles one has to play, was a survival tactic all the women had little choice but to learn.
Sources of Information

The difference between hearing about HIV as a disease and being diagnosed with it was a rude awakening. Much of the information about AIDS that the women knew from television, newspapers, magazines and friends that had made the subject previously interesting and conversational was suddenly, after their own diagnosis, revealed as useless, if not threatening. Despite the variety of ways that the women learned of their diagnosis, they all experienced a similar sense of disbelief. Diagnosed in 1985, Julie had not realized it was possible for a woman to have HIV. She had heard of AIDS only associated with men. Even three and four years later, at the time of the other women's diagnoses, little was available in print and the media to alter the stereotype of AIDS being essentially a male disease.

AIDS was known to be associated with death, however. Certainly in Heather and Julie's cases, their physicians believed themselves to be delivering an almost immediate death sentence to their patients. That their doctors had so little to offer by way of information or encouragement had a devastating initial effect upon the women. Used to consulting their physicians for comfort and cure, this response was deeply disturbing and left them with few options of where to turn for help.

Most of the women were recommended to make contact with an AIDS support organization. In the 1980's this usually meant contacting an organization that specialized in services catering to the gay male community most hard hit by the epidemic. AIDS organizations tend to provide a blueprint for survival for those living with HIV and AIDS. Prior to the advent of support groups specializing in their needs, women did not always find relevant role models or information and assistance adequate to their needs.

The women are all different in the amount of contact they prefer to have with AIDS organizations in their areas. Most take part in a support group for women and participate in organized speaking engagements, but some, for example Allison, Lynne and Heather, are more actively involved in organizational efforts. Participation has benefits
and costs. Involvement with AIDS organizations ensures a reliable source for information and contact with others who are HIV positive. As the category "women" is so inclusive, however, creating a women's group often means bringing people together who may have only their sex and disease in common. The efforts of all organizations to promote a focus on health and well-being is in part contradicted by the politically motivated choice to define people in terms of their disease as Persons With AIDS, or PWA's. While this is a useful strategy for minority association, public profile, and political lobbying, it feeds a stereotype of lives dominated by illness that many seek to overcome.

Coping Strategies

HIV happened to these women in the midst of busy, everyday lives revolving around jobs, relationships, appointments and responsibilities. The moment after diagnosis they all had to carry on. Running an errand, returning to the office, getting through the first few hours and days was automatic. Personal support, by way of a spouse, relative, or a friend was crucial at this time, but almost immediately all felt a need for more information. Contact with an AIDS organization and counsellor was recommended by most doctors. What the women were looking for were new possibilities. More or less familiar with the negative, they needed to know if it was possible to carry on, and how. Diagnosis left the women feeling helpless, vulnerable, and ignorant.

Meeting other HIV positive women was an event all women recall as having a significant impact upon their sense of self and possibilities. Just knowing another woman in a similar situation was out there helped to reduce feelings of isolation and estrangement, contributing to their ability to cope. Making contact with another woman meant making connections in other ways, too. In some cases, it meant tapping into an information and experience network, a private club with strict codes of confidentiality and almost unconditional emotional support. Informal women and HIV networks rely heavily on the telephone to bring women with HIV and AIDS together from different parts of the
province. In Heather's case, talking on the telephone was not enough. In order to meet with other HIV positive women she had to make it happen herself, with the assistance of the local AIDS organization group in her area.

All women said that finding out more about HIV and AIDS made them feel more in control. Self empowerment is the key to coping - fighting back in some way. Taking an active role in their own health care was one means of overcoming feelings of helplessness. Lynne found planning meals, taking moderate exercise and communicating with an network of informed friends more than just a comforting routine. To Julie, working out her vitamin regimen rewarded her with a sense of striking back at her illness.

Later on, community activism provided another level of empowerment for the women. All are currently involved in local AIDS organizations focusing on women's issues. Public speaking, telling others their story, is a continually reaffirming exercise. As there is usually no set format to the presentations, the possibilities for the individual to cater to her emotions and needs of the moment allows for a cathartic and therapeutic situation for the speaker.

Coping strategies also include avoiding certain situations or persons that excite negative feelings or stress. Since there is so much that cannot be controlled in life, developing the ability to take control over what aspects one can seems to have a significant positive effect on health and outlook.

Managing Contact With Medicine and Health Care Professionals

As an aspect of managing their health care, many of the women control their contact with doctors and health care professionals. The medical profession's focus on illness and disease offers little to women who are asymptomatic. Many find that discussions of HIV and AIDS from a medical perspective overwhelms their efforts to live life to its fullest. The difference between living with AIDS and dying with AIDS is a significant, rather than a subtle, difference. What makes maintaining optimism and a
forward-looking perspective so difficult for the women is that they are fully socialized into
the beliefs and understandings of the medical system they are attempting to avoid.
Physicians do not force their social and medical views upon us. We consult them because
we already share their views. Even in deserting them for alternative health or self-help
perspectives we carry our shared culture alongside our rejection. Taking a different view,
however, alters the normal relationship between doctors, medicine and the patient. To
step out of the traditionally subservient patient or sick role is to take on a more powerful
role.

None of the women entirely reject what traditional medicine has to offer. By
picking and choosing what health treatments they wish to participate in, the women have
become, more consciously, consumers of what the health care system has to offer. In
addition, their more active role allows them a greater potential for critically assessing what
treatments are available and what their risks and benefits might be. They see medicine as
valid for only part of their condition and seek other resources in themselves and the
community to learn to live with their illness.

Managing Intimate Relationships

Along with their diagnosis women may have to struggle with personal feelings of
discomfort and self-loathing related to the notion of their having contracted a contagious
disease. These feelings can intensify during times of the month that women have to deal
with mestrual blood. Few, if any, sources are available that offer discussion of the
connection between menstrual blood and HIV. Adding to the common cultural
secretiveness about menstrual matters, lack of information and lack of opportunity to
express their feelings and concerns can encourage in women negative emotional responses
to their own natural processes.

Aside from altering aspects of self-image, being HIV positive imposes many
changes on the nature of intimate relations between partners. Many women report losing
interest in sexual feelings and entering a period of celibacy. In part this can result from
undecided feelings, as in Julie's case, about how to deal with informing a potential partner.
For those already in an intimate relationship with a partner, the difficulties experienced can
be compounded by the fear of rejection or the disruption of the overall relationship. These
fears seem particularly prevalent when only one partner is HIV positive. In the case where
both partners are discovered to be infected, there may be a tendency to prolong a
relationship that might otherwise have ended due to the fears of both partners that their
chances of participating in another relationship are limited by their illness.

Initiating new relationships poses dilemmas of when and how to inform a potential
partner of one's HIV status. For Lynne, the situation was eased by her boyfriend having
previously learned of her being HIV-positive. Heather found it difficult to bring herself to
tell her boyfriend once they had started sexual relations. Knowing when and how to
reveal one's HIV status is a changeable and highly personal issue, fraught with influences
of power inequalities and sexual politics between partners.

There is little professional information available of how women's lack of
empowerment affects the heterosexual transmission of HIV. Prostitutes are frequently
blamed for the infection of women whose spouses or partners are the clients of the sex
industry (Anastos and Marte 1989: 11). Responsibility is shifted away from the man who
engages in risk taking behaviors. The prevailing ethic that considers it a man's perogative
to have multiple sexual encounters contributes significantly to the transmission of HIV,
particularly in the case of women who are not aware they are at risk (Anastos and Marte
1989: 11).

Education is only part of prevention. Even when a woman recognizes she is at risk
she may not be able to protect herself adequately. Current public health strategies rely
heavily on the use of condoms. The key problem with a condom is that it requires the
woman to assert dominance in the sexual act. Almost everywhere such dominance is not
the traditional mode and imposes unfamiliar behavior on both members of the couple
Ironically, women's control over their own fertility since the advent of the birth control pill, diaphragm and IUD has enabled men to relinquish active responsibility in birth control. Learning an interactive technique is a new experience for many couples. With the condom women are again responsible, however, on compliance by their male partners for their own protection. The condom has never been a particularly effective means of birth control (Zena 1990: 460). So far, research to provide reliable means that women could use to prevent HIV transmission has received little if any priority.

Sexuality is a key aspect of human identity. Problems resulting from the effects of HIV, medications, fears and diminishing self esteem through illness are particularly painful to the women. There is little opportunity or forum for them to discuss their needs and concerns centering on issues of sexuality. Once when Lynne tried to consult a nurse in the hospital about the use of rubber gloves during sex, she was told she was "disgusting". For Lynne and the others, rubber gloves are something they have had to learn to be comfortable with in order to safeguard their own and their partner's health. Safe sex poses many problems as whole patterns usually highly ritualized behavior must be altered to accommodate new equipment and practices.

**Managing Social Relationships**

In managing their social relationships the women have several goals in mind: the need to maintain their identity as a "whole" rather than an "ill" person; to protect their personal privacy; to safeguard themselves from rejection and negative responses; and to shelter those close to them from stigma. All the women were initially very selective about who they revealed their HIV status to. While most responses to their revelations were supportive, any negative response brought to bear a whole burden of societal stereotypes that the individual would then have to work through. The re-education the women themselves had undergone as a result of their own diagnosis does not protect them from
the knowledge of their own previously held stereotypes and prejudices which may, with the wrong encouragement, come back to haunt them.

Informing others is not an easy task even if the person is anticipated to respond in a positive fashion. All the women commented on the time and energy it took to pass on the bad news. Revealing one's status almost always seemed to include providing sufficient information to allow the person being told to properly contextualize the knowledge. Similar to their own experiences of first being informed, the women also find that telling others means dealing with people suffering a crisis of emotion who are not always receptive at that time to educational and explanatory information. It can be a time consuming and burdensome task.

The women's need to let others know about what has happened to them means opening their lives to the possibility of violations of their personal privacy. Heather found this to be the case when people she did not even know in her neighborhood began to approach her and question her about her status. Allison is one who is very protective of her family and is not willing to risk stigma being imposed upon her child before he has a chance to grow up and come to terms with his mother's situation. While all the women have participated in public speaking on the subject of their HIVness, not all of them are so open in revealing their status to even family members. Lynne, for example, decided not to inform her in-laws of her HIV status.

Being asymptomatic encourages the disguise of one's status, and perhaps, as in Heather's case, a certain level of denial. Certainly, while the women are healthy or while they have no visible illness, they have better control over who does and does not know their HIV status. Being able to live out a dual self-identity fulfills the special needs of women living with HIV and AIDS: the need for empathy for their being ill and their need to escape it.
Financial Impact of Illness

AIDS can be considered a disease of color and that color is green. On personal level, being sick is expensive even in Canada where health care covers many costs. Loss of employment earnings, loss of pension years, the need for child care, the need for home care, travel to medical centers for treatments, and medical costs not covered by health insurance, such as AZT\(^\text{24}\) and alternative therapies, are some of the cost related issues confronting those living with HIV and AIDS.

The impact of HIV and AIDS on one’s livelihood can be significant. Even though Heather was not ill at the time and was able to work, she could not get insurance for her day-care because she was HIV positive. She lost her job outright as a result of her diagnosis. Keeping up with medical appointments and drug treatments even before being ill was enough to interrupt the regular employment schedule for two of the other women. Lynne found it difficult to justify to her employer the amount of time off she required for doctor’s appointments. She had planned to keep her diagnosis private, but found she had to inform her superiors in order to gain the leave she needed for participation in drug trials at the hospital. Both Lynne and Julie eventually went on long term disability when minor symptoms and fatigue interfered with the proper fulfillment of their duties.

The economic significance of AIDS, extends beyond the personal. Despite the stereotype that AIDS affects only the marginalized and disadvantaged, those aged 20 to 40 and most central to the work force are most vulnerable to the disease worldwide (Treicher :52). That AIDS is the leading cause of death in women of this age group in some of the major cities of the Americas, Western Europe and Sub-Sahara Africa (Hankins 1990: 6), not only represents a direct impact upon labor, but also upon child

\(^{24}\) When AZT was released by federal authorities in 1986, British Columbia was the only province in Canada to refuse to provide AZT free to AIDS patients. Until 1991 it was available free of charge only to those eligible for welfare (Rayside & Lindquist 1992: 70).
rearing and care giving, two labor and cost intensive duties culturally defined as the responsibilities of women.

Social Identities: Being Managed

It is tempting to think of the women as individuals struggling on a new frontier of experience, except that women living with HIV and AIDS have been around for too long now to be thought of as a new phenomenon. In addition, the difficulties they confront are as much a part of their social context as they are of their personal lives. The extent to which they have learned to manage living with HIV and AIDS is shaped by the larger realm of social and cultural influences surrounding them. Women's experiences of illness are tempered by familiar and persistent conditions of sexism and marginalization encountered by women at all levels of our society. The situation for women is complicated further by the fear, denial, and homophobia in response to AIDS that deflects attention and understanding from a much needed focus on their needs and concerns.

Despite the fact that over a decade has past since AIDS was first recognized as an illness, that women are at risk has received little acknowledgment or attention. The reasons contributing to this are as complex and intractable as the disease itself and occur on a global scale: women are more often poorer than men; may have less access to medical treatment; may be preoccupied attending to the care of others; and are more likely to be in less powerful positions to negotiate relationships, in particular sexual relationships. AIDS tends to highlight weaknesses in the social order. For women, the overarching issue is sexism.

Gender Bias in AIDS Definition and Research

There is significant gender bias in our scientific and social understanding of AIDS. The US. Centers for Disease Control (CDC) determines the combination of opportunistic infections that justify an official definition of AIDS. The definition is based upon
symptoms appearing in mainly white, homosexual and bisexual men (McKenzie 1989: 5).

Further research into HIV and AIDS has been based overwhelmingly upon studies conducted upon men (Corea 1992: 76; Denenberg 1990: 32; Anastos & Marte 1989: 6; Ribble 1989: 35). Although this is not unusual in medical and scientific research, it overlooks the obvious: that women are also affected, and that women's bodies are different from men's. The differences affect both the consequences of HIV and the impact of medication (Scharf 1992: 189)

Women frequently are disqualified from participation in clinical drug trials. Ironically, the reasons given for their exclusion, are exactly the reasons why more research is needed. Exclusion is based upon the differences in physiology and hormones between men and women. The impediment to exploring such differences are said to be that it would require testing larger samples and increase the cost of studies (WARN 1989: 19). Many drug trials will consider as possible candidates only post-menopausal women or women who have been sterilized, due to possible risk to the fetus should a pregnancy occur (WARN 1989: 19; Scharf 1992: 189). The assumptions are that all fertile-age women are at risk of pregnancy and cannot be relied upon to use birth control consistently and successfully for long periods of time (Santee 1988: 12). Although concern for a potential fetus inhibits the participation of women, no consideration seems to be given to any harmful affect participation in a drug trial may cause to male reproductive capabilities or the risk of male participants producing defective offspring.

Lack of Diagnosis and Misdiagnosis

As a result of the exclusion of most women from studies, the clinical model of AIDS refers to many symptoms that are common in men, but unusual in women, and omits the kinds of opportunistic infections that women do experience. In 1987 the male-biased definition of AIDS was expanded to include, among other changes, conditions appearing specifically in HIV infected children. Ironically, although pediatric AIDS is a
reflection of AIDS in women, conditions exclusive to women are still ignored (Corea 1992: 76). Lack of studies, lack of knowledge, and lack of awareness all have consequences.

Not enough studies have been undertaken for confirmation, but evidence suggests that women have shorter survival times between diagnosis and death than men. Women with AIDS in Canada are twice as likely to have opportunistic infections than their male counterparts (Hankins 1990: 8). With few epidemiological studies on women, it is not surprising that doctors have difficulties recognizing HIV in their female patients (Hankins 1990: 7). With little understanding available of how HIV effects women's bodies, it is not surprising that women are often unable to recognize the onset of the disease in themselves (Taylor 1990: 10).

Around the world women are commonly misdiagnosed or late diagnosed with HIV (Fischl et al. 1987; Hankins 1990: 7). They often find out their HIV status as a secondary result of another medical intervention, such as the diagnosis of a partner, a blood donation, an illness, an operation or childbirth. In the case of childbirth, a woman may not learn of her own status until she is tested as a result of her infant's diagnosis (Spurgeon 1988:49-52; Hankins 1990: 448).

Although it is not commonly appreciated, there are patterns of AIDS-related illnesses more prevalent in women than in men, as well as conditions specific to women's reproductive systems (Scharf 1992: 191). Men and women have approximately the same rate of PCP. However, men are nine times more likely to get Kaposi Sarcoma (KS) than women25. Only 2.1 percent of female cases report this malignancy (Hankins 1990: 8). Early, non-specific signs of HIV in women include fatigue, fever, weight loss, diarrhea, skin rashes and vaginal infections (Hankins 1990: 8; Positive Women's Project (Victoria).  

25 Kaposi Sarcoma is a rare form of cancer that first appears as purplish spots on the feet and slowly spreads through the skin to the lymph nodes and abdominal organs. It occurs most often in men (Glanze 1985:407).
Although the natural history of HIV infection has not been examined sufficiently, reports document that recurrent or persistent yeast infection of the vulva and vagina (vulvovaginal candidiasis), yeast infection of the mouth and esophagus (esophageal candidiasis), abnormal pap smears, abnormal cell growth in the tissues of the cervix (cervical dysplasia) associated with genital warts (human papilloma virus, HPV), persistent or recurrent genital herpes infections, menstrual abnormalities and pelvic infections (pelvic inflammatory disease, PID), are typical clinical complaints suffered by HIV positive women (Hankins 1990: 8; Pinsky et al. 1992: 163-164). Adding to the difficulty of diagnosis, all these symptoms are not uncommon among sexually active women in childbearing years, except that in the case of HIV the ailments are particularly virulent and may only respond temporarily to treatment.

Lynne's repeated ear and throat infections over a period of eight months provides a representative example of HIV illness and its misdiagnosis by her doctor. Although Lynne had been told she was immune suppressed, her doctor did not seem to make any connection between the repeated infections. It was not until Lynne, in frustration, requested an HIV test herself that she was diagnosed.

Misdiagnosis often occurs as a result of lack of familiarity and knowledge of women's symptoms. Opportunistic infections that occur similarly in both men and women, however, are often misdiagnosed in women merely because there is little expectation that women get HIV and AIDS in the first place. PCP is the most common opportunistic infection in AIDS patients overall and is a major cause of AIDS deaths. Study results indicate that women with PCP who seek medical help are more likely to be treated for minor respiratory ailments and let go, while the same symptoms in male patients are recognized and treated as PCP (Anastos & Marte 1989: 7).

Heather's experience in hospital supports these findings. She was not diagnosed with PCP until two days after her admission to hospital when she revealed to the doctors her HIV status. Her PCP had not been diagnosed even though she did not respond to the
treatments given her, and even though there were other (male) patients in the same ward suffering from the same symptoms who were being treated for PCP.

Public Images: Women as Vectors

The media has confused the issue of the need for awareness among women by focusing on sensational headlines featuring the infection of female prostitutes (Taylor 1990: 10). The focus on prostitutes as vectors of disease has a long social history. There are numerous precedents for women prostitutes being scapegoated. Perhaps the best known instances occurred during World War I in America and Britain as a result of the high prevalence of venereal disease among troops (Brandt 1987). Venereal disease was then medically defined as being transmitted by women, and police and judiciary implemented measures to force women into medical quarantine (Scambler et al 1990: 264). Sexual bias is apparent in any metaphor that defines women as reservoirs of disease. The implication is that men are somehow innocent transmitters of sexual diseases, moving infection from one woman (a prostitute) to another (female sexual partner) (Murphy 1988: 72), rather than a potential source of infection themselves. Since the mid-1980's women prostitutes have been defined as causal agents, rather than as markers or victims of the spread of HIV and AIDS in the heterosexual population (Scambler et al 1990: 264). Some studies indicate that the prevalence of HIV in prostitutes so far tends to parallel the cumulative incidence of AIDS in other women (WARN 1989: 16). It is the high risk use of IV drugs, among a small segment of the total population, that is related to HIV among prostitutes (WARN 1989: 16; Scambler et al 1990: 264; Campbell 1990: 411). HIV antibody prevalence is three to four times higher among prostitutes who acknowledge IV drug use than among those who do not (Campbell 1990: 411).

The effect of deeply ingrained societal sexism is such, however, that until recently one could gain epidemiological information concerning women and AIDS mainly from perinatal studies and, to a lesser extent, from studies of prostitutes (Anastos & Marte
This has contributed to a skewed perception of the role of women in the AIDS epidemic so that they are regarded by the public and studied by the medical profession as vectors of transmission of the virus to their children and male sexual partners. This bias persists even though evidence indicates that the risk of transmission of HIV is more likely from men to women than it is from women to men (WARN: 6). And statistics show that there is only a 25 to 50% chance of transmission of HIV from mother to child though childbirth (Campbell 1990: 410). There is little discussion of women's concerns as people with HIV and AIDS who are often themselves victims of transmission from the men in their lives. While she received the virus from an anonymous source, the callousness of Laura's doctor to the discovery of her being HIV positive provides a case in point. Overlooking her feelings entirely, the doctor only expressed concern for the surgeons who had operated on her.

Speaking Out

All of the participants in this study could be described a private people. Yet, as a result of their experiences with AIDS, stereotypes and stigma they have been motivated to speak out. Time is precious to them, but they are committed to educating others about the risks of HIV and AIDS and the inequality, injustices and sexism suffered by women who find their lives suddenly transformed by this chronic, stigmatizing illness.

For the participants, the study has provided an opportunity of several different kinds. Speaking out is not always an option for women, wishing to maintain control over who knows of their HIV status. This study offered the women a protected, anonymous opportunity to tell their stories. In addition to helping to document models for women's experiences living with illness, the women gained a sense of personal power and achievement from their participation. Through the study they have been able to affirm to themselves and others what they feel is significant about their lives with HIV and AIDS.
Chapter Four

Where Are Allison, Lynne, Laura, Heather and Julie Now?

It has been three years since I first interviewed Allison, Lynne, Laura, Heather, and Julie. Of course, their stories do not end in these pages, but continue on. Many changes have taken place for each of them. I felt it only appropriate to give them an opportunity to update their situations. I requested that each of them send me a letter commenting on what changes have occurred in their lives with regard to their personal status and health, plus any additional comments they wished to add to what I have already included.

In response, what the women have to say is full of promise and pain. The coexisting conflict between these two states is best represented in the way that all of them make use of the expression "being positive". Allison, Lynne, Laura, Heather, and Julie throughout the years of our collaboration have all used "being positive" at times to refer to their HIVness and at other times to their commitment to carrying on meaningfully with their lives. Both illness and cure, being positive is not merely a contradiction, but an accomplished way of living the women have struggled to achieve for themselves.

Allison

With energy and perseverance, Allison manages many roles in her current routine; that of busy parent of an active toddler, partner in a committed relationship, dedicated worker for the rights of HIV-positive women, counselor to newly diagnosed HIV-positive women, and an HIV-positive self. She is often tired. Although she is not as well, physically, as she was at the time of our first interview, she is just as adamant as she was then about living her life to its fullest.
Allison and David have sold their apartment and purchased a large, stately home with a rental suite in the basement and a large yard. David has been successful in a new job that provides them with more financial potential and stability. Allison has now retired completely from her professional career in favor of being a full-time mom and part-time AIDS worker.

Undoubtedly, the most significant change in Allison's life has been the birth of her son, Alexander. She is convinced that her pregnancy and labor did not adversely affect her health status, and with the confirmation of her baby's healthy immune system, she and David were spared any possibility that their worse nightmare - their child being infected - would come true. Raising Alexander is demanding, however, and Allison feels the interference of her illness in her best efforts to provide for her family:

I have a healthy happy two and a half year old boy who brings more joy and benefit to my life than any chemical medicine could. I love being with him and know that it was a good decision for us to have him. I would not necessarily counsel another woman in my position to do the same [however], knowing what I do now about the demands of parenthood as well as the debilitations of HIV. I have more familiarity with [that] than I did three years ago.

While Allison's health status remains fairly stable, she is now persistently bothered by HIV-related symptoms. Well read and well-informed in the latest treatments and medications available, she has become skeptical of the efficacy of new medications that appear on the market at fairly regular intervals for treating AIDS. In the last year she has decided to take even more control in decisions effecting her health:
I stopped taking AZT last year and have really felt no difference, except freer psychologically. I have become more in charge of my own health care, including exploring alternative or natural options. I am not prepared to let anyone else take responsibility for my health care decisions. This is sometimes extremely hard, as it would be nice to have someone say "Don't worry, just do this and everything will be all right". But it is not a reality. AIDS is a very fashion-driven illness. The experimental drug-of-fashion this year will be out of style by next year. I am the only one with enough stake in my life to make the right decisions.

As well as having to come to terms with her own health situation, Allison has had to observe the debilitating effects of HIV on close friends around her. Confronting the death of others has left her little room to avoid facing the thought of her own mortality:

In the past year I have faced the deaths and severe illness of some of my HIV-infected friends. Along with this has come a facing of many of my own fears. It has been a difficult time for me, and has brought home to me the fragility of my own life. I feel as though I've had to unlearn and relearn many assumptions I've carried for years. In addition, I've developed a persistent rash on my neck, chest and ears, which has fed my fears around HIV, pain, and death.

The onset of her first visible symptoms of HIV-related illness has had an impact on her relationship with David. The complexity of what a non-infected partner experiences when faced with a loved one's affliction, unfortunately tends to increase just at the time when his or her support seems most greatly needed. The intense evolution of values, emotions, and priorities that Allison feels as she deals daily with a heightening sense of her
own mortality is, not surprisingly, sometimes at odds with her spouse's feelings. The pressures they experience, originating from a common grief, can pull them apart:

I am struggling in my relationship with David. Our sex life is non-existent since I developed this rash. He is even reluctant to touch me unless I am clothed. With all the emotions and losses I've had to deal with recently, I have moved into a place where I don't take anything for granted, and I try and live my life day to day. He doesn't understand this and feels I should be "more responsible" financially. He is focused on his financial responsibility (we have a significant debt), while I am focused on experiencing life. This difference in perspective means that he sees my desire to go out for dinner once in a while as frivolous. I see it as nurturing our relationship and feel a great sense of loss. I no longer take my tomorrows for granted.

Commenting upon her earlier contributions to this study, Allison wonders at the changes she has experienced since then:

Re-reading what I said three years ago, I am amazed at how optimistic I was then. Although I am still optimistic, I suppose my view of life is tinged with some of the sad realities I have learned in the intervening time. I've spent a great deal of time in the last few months trying to understand my spiritual self, needs, and framework. It has been both difficult and satisfying.

Allison finds great satisfaction in offering her own hard won knowledge and experience to others newly diagnosed HIV-positive. She gains a sense of achievement in
knowing she is personally making a difference. Her work at the Positive Women's Network (PWN) is an investment in her own, and other's, future:

I have been contributing time (both paid and volunteer) to the Positive Women's Network. I find it satisfying to be able to talk to newly diagnosed women and help them get accurate information, as well as be a voice of hope for them in a sea of negative advice. We have great plans. There are more and more HIV-positive women coming out of the woodwork. Many have been infected by a man they slept with/dated/loved. "I didn't think it could happen to me", is still the most common thing I hear them say. I am sorry for every one of them that I encounter, but I am glad we are coming together more. These women are all my heroes. Our struggles have not been told yet. One day I will attempt this.

Lynne

Lynne and her fiancé, Ron, were married in August of 1990. Over the last few years, the love and optimism that brought the two of them together has been eroded somewhat by the strain of living with HIV. Lynne is currently unemployed and living on disability. She retired because of fatigue and general HIV symptoms. Although she has not yet suffered an AIDS defining opportunistic infection, Lynne's health is poor:

My T-4 cell count is 180 on average and my energy level is low. I need to nap most days. I am currently taking AZT/DDC combination therapy, as well as a thorough vitamin regimen. I take Septren as PCP
prophylactic, Acyclovir for herpes, Losec for stomach acidity, and over the counter (OTC) medications, e.g. Tylenol as needed.

Increasingly physical manifestations of HIV illness place a mounting burden of worry and fear on Lynne's relationship with her spouse:

My marital sex life has fallen prey to HIV disease. As Ron has become more aware of AIDS and my possible mortality he has become afraid. The fear of my death or of him catching the virus has taken its toll by shutting him down sexually. In the past two and a half years we have become less and less sexual, until now the agreement is we learn to live without. This change has been devastating for both of us. In a day to day sense we carry on much as before. We're affectionate, hug and kiss, and share most of our lives, but I don't think the lack of intimacy will do us good in the long run. I worry about both our futures - issues around our marriage's strength, and individual self-esteem are of great concern.

Lynne is convinced that the problems she and her husband are facing are not uniquely theirs. She feels the need for a support group to share feelings and experiences with, such as the changing responses within a relationship confronting HIV. She is working to help organize a group to deal directly with personal issues.

Lynne works two days a week at the Positive Women's Network (PWN) and also does guest speaking on AIDS through the AIDS Vancouver Speaker's Bureau. Lynne finds her volunteer involvement and public speaking to be "empowering". Yet, the energy she expends in positive efforts for women and AIDS on a community level seems equally matched by insecurities and doubts she entertains on a personal level:
It is tempting to make my life smaller - drop peripheral friendships and involvements, let go of casual hobbies etc. The desire to make myself ephemeral in my own life has been present and, I think, damaging to me in the past year. By ephemeral I mean that somewhere deep inside I've decided that if I live my life leaving no permanent markers, those who are left when I die will have less to miss, and therefore less to mourn. This desire also comes from societal pressure to see myself as disabled, unable to contribute to society, of less value, "dying" and, therefore, in some sense, already gone and not to be included.

Death, Lynne tells me, is by now a familiar subject and no longer a topic she wishes, or as a matter of fact can even try, to avoid:

I have lost my immediate fear of death. I've lost so many friends now (thirty in six years), that I've had to really think about what death means to me. I've come to a fairly consistent state of calm acceptance, and developed a belief system around what will happen after I die. It's been comforting.

Comfort comes from strange places. Mostly, it appears, from within. Lynne depicts HIV as an intensely personal journey, yet one that is constantly influenced by larger society's cultural values and judgments. It is often a lonely experience:

I face stereotypes in the media that tell me I have no right to a sex life, [to] bear children, and [that I] should be grateful for whatever support I get from others. It's hard to live a full, active life even though I live in Vancouver which is a fairly developed city in terms of philosophy and
resources. I have a great deal of support from family, co-workers, and friends, yet I still feel I journey with AIDS alone. I think this is because AIDS touches the deepest, most personal areas of my soul, body, and mind. They are reaches that are occasionally shared with others, yet I live them every day. Somehow, this account feels incomplete, perhaps because the story is ongoing and- for me - has not ended yet.

Laura

Since the time of our first meeting, Laura has developed a passion for educating others about HIV and AIDS. To her busy social life that includes frequent trips abroad with her husband, Laura has added an impressive schedule of public speaking. The first time she spoke before a group was in the spring of 1990. It was in an elementary school to a class of Grade six students. She spoke to them as a grandmother living with AIDS:

They were so interested. Lots of questions. I had been warned they would fidget and not ask questions. I handed out paper for them to write questions on. They were not needed. I now knew there was a purpose for my having this virus!

Following this speaking debut, Laura went on to give numerous newspaper, radio, and television interviews. At first she went under the guise of a pseudonym, later she began to use her real first name and, now, she proudly uses her real, full name. One of her grandsons, with permission from his parents, appeared with her on a CBC French TV news program. The show was so successful the interview was shown on the English news both locally and nationally. Laura was featured on the front page of the Vancouver Sun
newspaper and in a poster to promote awareness on World AIDS Day, December 1, 1990. That year the World Health Organization sponsored event focused on the topic of women and AIDS. She has spoken to AIDS Vancouver training groups, church groups, to college students and health care workers. Currently, Laura does telephone consulting with women usually near her own age who prefer not to participate in group meetings.

Laura's decision to go public with her experiences living with HIV carried not only herself, but her family as well, into the limelight. Initially, Laura's husband, Robert, was nervous about what kind of response she and the family might receive. There was, however, no negative backlash, just Laura says, "support and lots of interest". Robert took early retirement in October 1990. Despite Laura's fluctuating health, the couple continue to travel extensively.

The letter Laura writes updating her activities over the last two years is unique in the way it documents a seemingly incongruous combination of travel destinations and HIV-related illnesses. Laura seems to counteract every health setback she suffers with a journey for joy:

March '91, we flew to Orlando, Florida. I thought my legs would burst. My T-cells were below 200 now. We were meeting our son Mark and his family in Disneyworld. They were coming from Colorado. We had a great time, but I was not well. I saw my doctor on return. He made an appointment with a specialist about my legs. The specialist said it looked like I'd had [varicose veins] for at least 10 years. He performed day surgery, cutting the arteries on top of my inner thighs to relieve the pressure. My T-cell count had dropped to 140 and I was taken off AZT.

I was put on DDI as I left on an Alaska cruise. All went well. I began to improve. I kept on with my trips and speaking engagements. By September '91, my T-cells were 400! My doctor thought I should try AZT
again with my DDI. I started feeling ill almost immediately. The third day
I couldn't get out of bed. I stopped the AZT, but now DDI wouldn't help
me anymore. My T-cells were falling again. February '92 my T-cells were
140.

March '92 we left on a Grand Circle Orient Cruise. I was just
beginning to feel better. We had booked in January '91. I had been so
sick, I just had to have something to look forward to. Our 40th [wedding]
anniversary was February 9, 1991. The cruise is what I wanted for a
present. My husband obliged. It was wonderful, worth every penny! We
returned May '92. On return my T-cells were up to 160.

Laura writes that her son, Paul, has moved back to Vancouver from the United
States. He works as a self-employed systems analyst, has much energy, and travels a great
deal. So far, he has not been ill and his T-4 cell count is around 700. She also tells of the
birth in February of 1991 of her sixth grandchild. The child, a little girl, is named Laura
Clare after her two great, great grandmothers.

Laura suffers a range of HIV-related symptoms: an ulcerated esophagus and
mouth, oral thrush, weight loss, xerostomia (lack of saliva in the mouth), fungal infections,
and peripheral neuropathy (numbness) in her legs. As of December 1992, however, her T-
cells were 210. She says she "has never felt so well over a winter for a long time". Laura
continues to plan for her future.

Heather

Although poor health and chronic fatigue plague her, Heather entertains a taste
and vigor for life that is both cheerful and refreshing. Four months ago her T-4 cell count
was measured at 70. She has suffered two significant bouts of pneumonia and pleurisy
since then. Struggling now to recover from her latest illness, Heather did not feel she had the time or energy to send me a written update. Instead, we spoke together over the telephone and agreed that I would paraphrase what she had to say. She also gave me permission to use excerpts from a letter she had written to me in 1990 in response to her receiving a copy of our interview tape. In the letter she described to me her satisfaction with being able to listen to herself tell her own story:

Listening to the tapes was really interesting. Besides not having much opportunity to hear my own voice, hearing the whole thing from beginning to end was really something. I shared the tape with a couple of friends. Their reaction was, Geez, it took us a whole year to get all of that out of you!

Shortly after she wrote me this letter, Heather moved from her rental home into a government subsidized apartment in a different part of the city. The move was not an easy one. It represented increments of loss in several ways to her: loss of employment, loss of independence, loss of space; loss of the way things were before:

It was hard to let go of my house and move into an apartment. Sort of yet another process of letting go and accepting the changes that have taken place in my life as a result of having AIDS. I suppose there will be a few more [changes] even yet.

There have been many changes, however, Heather and her, now eight year old, daughter are doing well. Her daughter has literally grown up with her mother being ill. Heather maintains an open dialogue with her, allowing her to express her anger and frustration at her limitations and the times that she is just too sick to be active with her.
Heather is particularly grateful to her Sterling network. The eight-member, women's group meets once a week and are more like family than friends in the way that they step in to help out whenever necessary. Their unconditional assistance and support, Heather believes, has allowed her to keep her daughter at home and in her care without social service intervention.

Despite regular flu symptoms, frequent yeast infections and her recent bouts of pneumonia, Heather describes her health as "good". She has not, aside from the PCP three years ago, suffered any major opportunistic infections associated with AIDS. She credits her relatively stable health to her choice of a naturopath as her primary health care physician and her decision not to take AZT and related drugs. Part of the success of her health regime is undoubtedly the strength of commitment she is willing to demonstrate in support of her own choices.

Social services provides payment for a wide variety of special health care needs for its recipients, but does not provide funding for any natural health care regimes. Heather took Social Services to court on this issue three years ago and, along with three other people in Canada, won the right to receive payment for alternative health treatment. She found the process of working through her claim with an advocate and making her presentation to the tribunal energizing and empowering. Heather consults her naturopath twice a week, but does not refuse more conventional treatment or drugs in critical health situations.

The relationship Heather was struggling with at the time of our first interview ended shortly after. It was a painful time for Heather. She rallied, however, and eventually struck up a friendship with a man she met in the neighborhood. He moved in to live with her, more as a house mate than a partner, for a year and a half. Their close, and sometimes intimate relationship, ended for similar reasons, Heather believes, her previous relationship had. The cause being, as Lynne so eloquently described in her story, "disease" with disease: fear of contagion, the discomfort of living with someone who is
believed to be terminally ill. Ironically, Heather finds that inhibiting feelings occur later, rather than sooner, in a relationship. The change from full intimacy to increasing physical distance is devastating as it happens. Heather's fears of being alone have not been lived out, however. She recently met someone else, also a single parent, through her daughter's school. While he is eager to formalize their relationship through marriage and have her and her daughter move in with him, experience makes her cautious of how long these feeling might last. She knows it is very difficult to watch someone suffer. She wants to protect what control and stability she can maintain in her own and her daughter's lives.

Heather tells me she feels that her family relations are growing closer. She is in contact with both her parents and her brothers. Her mother came over from the mainland during Heather's last hospital admission to stay at the apartment with her daughter. This was the first time her mother had left her own home to come and help her out. Heather says she regularly sees one of her brothers, also from the mainland, whom she has appointed legal guardian of her daughter if she should die.

The most frustrating thing with having AIDS, Heather says, is not being able to work. She tried to take a job cleaning an office for two hours a day, but found she could not keep up with the physical demands it required. She has kept herself busy, however, making her own opportunities. She and another friend have been sewing hats and selling them locally for some time now. The intermittent labor this entails better suits her capabilities. A year and a half ago, she tells me, she quit her volunteer work at AIDS Vancouver Island (She still attends, however, the weekly meetings of the support group for women with HIV and AIDS.).. After five or six of her friends died within a short period of time, she says she felt the need to get away from the focus on AIDS and channel what energy she had in a different direction. Feeling the need to express herself creatively, she took up acrylic painting on canvas. Soon she found herself with enough paintings for a one woman show, which she held in a privately owned space in the city. The show was a great success. She sold all the paintings she had not already given to family members, as
well as over 100 greeting cards printed with photos of her work. Since her latest illness, Heather has not done much painting. She is confident, however, that her condition is improving and she hopes to do more soon.

Heather finds that achieving a balance between AIDS related interests and non-AIDS related interests is the key to successful well-being. She basically has two networks of friends, those with AIDS related interest other HIV positive people and people she has met through the AIDS Vancouver office, and other friends whose interests in AIDS are incidental. She is rightly proud of her efforts in sewing and painting, and gains much joy in their pursuit. Heather does not relish being ill, but she is enjoying life.

Julie

Much has happened to Julie in the time between our first interview and now. In a lawsuit that is the first of its kind in Canada, she sued the doctor who performed the artificial insemination that resulted in her contracting HIV. She sued for expected loss of future income and reduced life expectancy. The doctor, a prominent Vancouver obstetrician and gynecologist, denied liability, claiming that medical science was not aware at the time she was infected that the virus could be transmitted in such a manner (Hall 1991a). After two weeks of trial proceedings, a civil jury made up of seven women and one man, decided on November 20, 1991 that the doctor was negligent (Hall 1991d). An Australian immunologist testified that artificial insemination clinics were shut down in that country in 1984 after it was discovered that four women and their children were infected. The doctor published an article alerting the medical world to the problem of transmitting HIV through infected sperm in the British journal *The Lancet* in 1985. The Australian doctor testified that although the mode of transmission of HIV was confusing in the early days of AIDS, public health officials should have been more active in advising proper screening tests be done of blood and semen donors (Hall 1991c). Julie was awarded a total
of $883,800 in damages: $460,000 for pain and suffering, loss of enjoyment of life and reduced life expectancy, $3,800 for out-of-pocket expenses before trial, $65,000 for loss of income, $280,000 for future loss of income, and $75,000 for the cost of future care (Hall 1991d). The doctor has since filed an appeal on both the ruling and the damages. The results are still pending. Almost $200,000. of the award has been advanced to Julie. The remainder of the award is held in trust, pending the outcome of the appeal. Julie used the money she received to pay off her legal fees and to put a down payment on a new house (Canadian Press 1991).

Although hopeful about its eventual outcome, Julie found the trial exhausting and was glad to be back to her own routine. She has received many requests for interviews as a result of the publicity surrounding the trial. She has taken advantage of the opportunity these requests have provided for her to talk about her own experiences and to promote awareness of HIV and AIDS.

Julie writes me that shortly after our first interview in 1990, she experienced a "transformation" in her inner self. This was precipitated by three events that, together, gained great significance for her:

I found Love inside me. Surprise! Before this I always vaguely wondered what love was and if I had any, and how could you tell? I wasn't looking and I found it right inside. Very big. I had intuitively refused AZT, feeling it would be destructive to my body. Later that year I stopped using a visualization tape that was a bit too hostile or destructive to the virus. I was becoming a true pacifist. Later, again, I cut myself and had to be stitched up before I went to a [choir] rehearsal because I could not go there with all this "dangerous" blood around. When I came home that night I had a spontaneous chat with my blood, reassuring it that I like it just fine, even if others were afraid of it.
Not until some months later when these three things came up in a presentation, did it hit me: I LOVE THE VIRUS - IT IS ME. There is no distinction of 'you' versus 'me'. We are all ME, and I love ME. Therefore I love the virus. Weird. Powerful.

Julie comments that people may think she is crazy, but that she feels free to have non-conforming thoughts about her illness. She continues to avoid doctors and the standard medical treatment for HIV, such as AZT, in favor of alternative therapies. Her efforts to keep a positive focus, she explains, can be put off by a visit to the doctor:

You go to the doctor feeling fine. He finds a little abnormality somewhere and has you bringing in all kinds of samples, [taking] X-rays, other tests, and seeing a specialist. He is ruling out the things, but the things he is ruling out are HIS focus. And your schedule becomes focused on illness, not health. Doctors look for trouble. If they persist long enough our bodies oblige miraculously.

Julie has found that her emotions have a significant impact on her health. She makes a conscious effort to focus on good feelings and good thoughts, despite the death of many friends around her. Julie tells me how she and another HIV-positive woman friend compared their experience with frequent death with what it must have been like in wartime London during the blitz:

A casualness about our friends dropping dead. "John and Ann down the street got hit. Too bad. Let's go get something to eat". I realized that we live in a different world than most people now. Many PWA's lose not only one close friend, but a whole bunch of their friends. I
thought the people [at my] bridge club would be different if 20 of the youngish players had died in two years and [there was] no end to it.

One death has particularly effected Julie. His name was Geff. She knew him only briefly before he died of AIDS in July of 1991. They had much in common, a love for music, and, as it turned out, a distant family connection. With no relatives in Canada, and 6,000 miles from her homeland, Julie feels the meeting was not a coincidence. The spiritual connection she made with Geff and his remaining family continues.

Julie's health has remained stable, although her T-4 cell count varies. In 1992 it dropped from 920 to 700 and then to 500 and 480. Her last count was up again to 480. Julie writes:

I must add that [a] T-4 count is only a small part of the picture and not too much importance should be given to it. People with T-4 counts of 0.0 are alive and well. Some die with fairly high counts.

Julie says she is still learning and developing in how she deals with HIV. She is learning to trust in herself and in her body. She still feels she has a message to deliver to others. The message has changed somewhat from before, however:

Since the courtroom I have had more publicity. Some I feel good about, some neutral, but I welcome the chance to say something important and stay away from focus on how I got it. That was just the vehicle that brought me and publicity together. My message now is not only: Look at me - anyone can get it, but also HOPE for PWA's, an attempt to open people's minds to new possibilities of thought. I try to communicate what the bigger message is. I believe that AIDS is not necessarily fatal. The
more people leave a window open for that possibility, the more power it will have. The outcome depends very little on what specific treatments a person chooses or allows, but a lot on what one's mission is in life, what one needs to learn, one's karma.

It comes full circle: AIDS is here as a manifestation in our bodies of what we have done to the planet and we are still not seeing the light. Not quite yet, that is. But there is hope that it will happen. I do not believe AIDS [will be] cured in a laboratory. It will go away when humanity learns to take care of its common residence, the Earth, and love and accept each other.
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APPENDIX 1

** REQUEST FOR VOLUNTEERS **

HELLO!

Would you be willing to participate in an anonymous, confidential study about women living with HIV/AIDS in British Columbia?

My name is Carol Howard Donati and I am a graduate student in Anthropology at the University of British Columbia. I am working on my Masters Thesis on Women Living with HIV/AIDS. I would like to interview women (the session will be tape recorded) who have HIV/AIDS about their experiences living with the illness. Information from the interviews will be used in my thesis and possibly in other published resource or educational materials. The purpose of my study is to describe women's experiences living with HIV/AIDS in British Columbia based on women's OWN descriptions. This work is intended to raise awareness and concern about issues identified by women whose lives are most directly affected. Interviews with a range of different women will reveal common areas of concern among women living with HIV/AIDS as well as important differences in their experiences and needs. Such a document will be an important resource for informing and educating others.

I am interested in hearing about YOUR experiences. The interview session will last about two hours and will take place at a time and location that is convenient to you. Your participation will be anonymous. The only person to know your identity will be myself. So your real name will not appear anywhere on tape or in print, your identity will be disguised by a pseudonym. If necessary, identifying details of your personal history may also be altered to ensure confidentiality.

You are not required to answer any questions you do not wish to, and you are, of course, free to withdraw from the interview at any time you wish to without prejudice.

If you have any questions about the study or you would like to take part, please feel free to contact me. I'm looking forward to hearing from you. Thanks.

Sincerely,

Carol Howard Donati
APPENDIX 2.

STUDY OF WOMEN LIVING WITH HIV/AIDS
VOLUNTEER CONSENT FORM

I agree to be interviewed in an anonymous, confidential session by Carol Howard Donati for the study Women Living with HIV/AIDS. Information from my interview will be used in the production of a Masters Thesis in Anthropology at the University of British Columbia and possibly for further educational or resource publications. The purpose of the study is to describe women's experiences living with HIV/AIDS in British Columbia based on their own stories.

The interview will last about two hours. If necessary I may participate in a follow-up interview of no more than two hours. I agree that the session will be tape recorded and, if I wish, I will receive my own taped copy of the interview.

My contribution will be completely anonymous and confidential. The only person to know my true identity will be the interviewer herself. My real name will not appear anywhere on tape or in print (although I agree to sign this form below with my true initials). Where I am referred to on tape or in print my true identity will be disguised by a pseudonym. I do not need to answer questions if I do not want to and I may withdraw at any time from the interview without prejudice.

The interviewer is willing to answer any questions about the project in person, in writing or by phone.

I have received a copy of this form.

Date ____________________ Name ____________________
* Only first and last initials of your real name are required.

You may refer to me by this name: ____________________

I can be contacted at: ____________________

______________________________
APPENDIX 3

STUDY OF WOMEN LIVING WITH HIV/AIDS
SAMPLE INTERVIEW QUESTIONS

(Note: These are sample questions. Wording etc., may vary depending on person being interviewed.)

Introduction: I am interested in hearing about your experiences living with HIV disease/AIDS.

1. When did HIV disease/AIDS first become a concern in your life?
   Where did you first hear about AIDS?
   How did you find out about your own status?
   How long have you been living with HIV disease/AIDS?

2. What experiences in your life do you feel are associated with your illness?

3. HIV disease/AIDS affects every person differently. Tell me about your experience.

4. Is confidentiality an important issue for you?
   What sorts of things do you do to keep your status secret?

5. How has living with HIV disease/AIDS affected your life?
   Your relationships with others?
   Your work?
   Your attitudes towards yourself?

6. What sorts of treatment have you been involved with?
   Medical? Non-medical? How do you feel about this treatment?

7. What things have you found most helpful to you in coping with the illness?

8. Have you thought about dying?

9. Do you know other women with HIV disease/AIDS?

10. How did you make contact with them?

11. Do you participate in any organizations or support groups for persons with HIV disease/AIDS?
    Are they helpful?
12. What services and/or resources would you like to see to help women living with HIV disease/AIDS?

Thank you very much for participating.