UNCOMFORTABLE COMPANION: THE EXPERIENCE OF LIVING WITH HIV AND AIDS

orchestrated by:
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B.N., University of Lethbridge, 1988

through the voice of:
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MASTER OF EDUCATION

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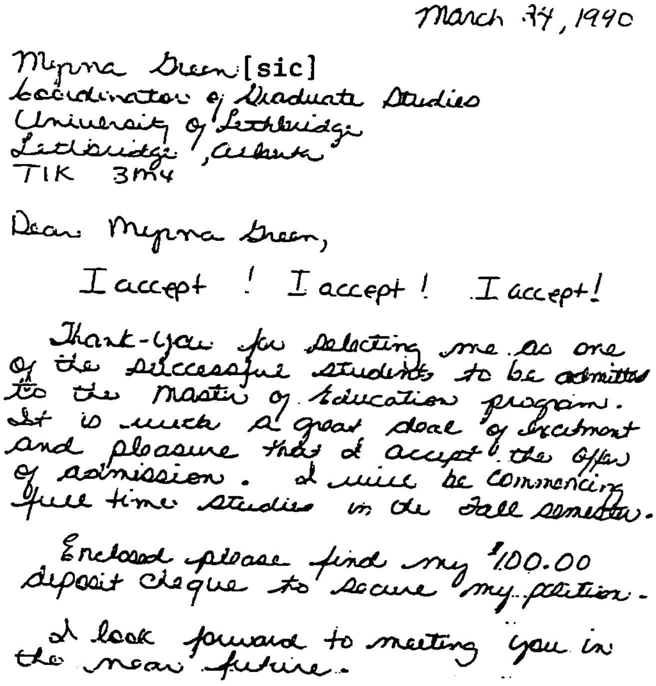
Respectful Acknowledgements

I had no idea the impact of this handwritten note of acceptance would have on my life. . . .



March 24, 1990

Myrna Green [sic]
Coordinator of Graduate Studies
University of Lethbridge
Lethbridge, Alberta
T1K 3M4

Dear Myrna Green,

I accept ! I accept ! I accept!

Thank-you for selecting me as one of the successful students to be admitted to the Master of Education program. It is with a great deal of excitement and pleasure that I accept the offer of admission. I will be commencing full time studies in the Fall semester.

Enclosed please find my $100.00 deposit cheque to secure my position.

I look forward to meeting you in the near future.

Contemporary people may say, "Joan, you have experienced a paradigm shift!"; I say that I have indeed been fortunate to embrace the most enriching educational experience of my life. I extend a sincere "Thank-You" to all the people in the Faculty of Education. It is the wisdom, sensitivity and uniqueness of these individuals that contribute to create this incredible graduate program.

Dr. Cynthia Chambers

Dear Cynthia,

Thank-you for your patience and gentle persuasion to encourage me to internalize and value the need to write. Through your writing about the Dene people, I learned to listen, respect and honor the stories of others. I am proud of my writing for this project and feel I have documented an important personal history that may have otherwise slipped past unnoticed. The pride I feel in my writing is the direct result of your guidance; you managed to focus my attention, challenge my abilities and nurture my confidence. Sincere warm hugs.

Dr. David Smith

David, in many ways you are responsible for the tone of this project. The courses you taught altered my philosophy of education, challenged my notion of what it means to be human in this world, and matured my level of consciousness of global concerns. In one class you mentioned that true learning only happens when the person experiences a burst of insight echoed in an "augh haw" response of knowing. I am grateful that I listened carefully enough to recognize my "augh haw" response and continued to explore the question, "What is the experience of living with HIV?".

You are an excellent teacher and a wise, sensitive person. Thank-you for trusting in me.

Carillon Purvis and Ingrid Pearson: True Feminist Warriors!

Heartfelt thanks for your ongoing support, advice, love, and enduring friendship. Over the past few years, to be my friend required stamina and inner strength above and beyond human capabilities. Care-a-long, thanks for the energy and light. Ingrid, I appreciate the peaceful calmness of your presence.

May 27th, 1994, I shall convocate with a Master of Education degree. The parchment will only reflect my name, but I have not accomplished this achievement on my own. For this occasion, I wish I had a huge Chinese dragon costume to promenade across the stage, because I want all these people to join the parade and share the limelight: JoAnne, Sarah, Adam, Joanne, Bill, Jean, Wendy, Linda, Darlene, Lil, George, Shirl, Deb, Denise, Mom and Dad, John, Brian, Walter, other faculty and the dozens of other people who have encouraged me.

Wayne,

My soul-mate; I love and honor you.

Uncomfortable Companion:
The Experience of Living with HIV/AIDS

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Roots of the Question

The question "What is the experience of living with HIV/AIDS?" had a very slow way of attracting my attention. Early in the 1980s, I remember hearing about a strange condition called "gay cancer." At that time the popular press was describing how young homosexual men in San Francisco and New York were dying as the result of this unique cancer (Shilts, 1987). The press was reporting the incidence of these unusual deaths and the emerging political action, as the gay communities in these major cities slowly became aware of the magnitude of this disease. The gay political action groups were struggling to convince the health professionals to pay attention to this new cancer.

Initially I read newspaper articles about gay cancer and later began seeing brief articles in professional medical journals. Those early articles painted a gloomy picture of the process of this disease, and highlighted the destruction of the individual's immune system leading to eventual death. The disease appeared to infect one specific group of persons, namely urban homosexual men. As a result of the immune system involvement of this specific group, the name of the disease shifted, and gay cancer became known as "Gay Related Immune Deficiency" (GRID).

In 1986 while I was taking an epidemiology course, my curiosity and interest in this dynamic retrovirus intensified. By this time French researchers had isolated the antibodies produced as the body's response to the retrovirus HIV (Human Immuno Deficiency Virus), and the label GRID changed again to the current label "Acquired Immune Deficiency Syndrome" (AIDS).

Researchers had also concluded that this was a blood-born pathogen and was transmitted when the blood or body fluids containing blood of an infected person had a route of entering an uninfected person. The two North American groups most infected with HIV at this time were homosexual men and intravenous (I.V.) drug users. The patterns of transmission of HIV were focused on the sexual behaviors of gay men and needle sharing habits of I.V. drug users. I felt comfort and smug security in the notion that HIV/AIDS only happened in distant urban environments. To me this topic was of academic interest and challenged my intellectual and professional abilities as I read to develop a knowledge base related to this remote condition.

In 1987 while working in a local emergency department, I was confronted with my first "clinical case" of AIDS. The scene as it was played out in that emergency cubicle can not be described as a clinical interaction, but rather as an intense emotional blending of two persons' realities. The reality of a young man with pneumonia and his recent medical label of HIV positive, and my reality that this disease was no longer only of remote academic interest. As a health care professional I was confronted with a new phenomena, a contractible, fatal disease. HIV now existed as part of my professional practice. Despite all the reading and speculating I had done about HIV/AIDS, I was unprepared for my own reactions during this initial interaction. I remember feeling the gut-wrenching fear of the unknown territory where professional knowledge meets embodied experience.

To this day, I feel the heart-pounding panic and the desire to scream as I speculate about my previously "safe" work environment which had just been invaded by an alien black force, the mystery of HIV.

Clinical Reality: Face to Face

All the nursing tasks I had done a million times before suddenly became an awkward challenge. Starting the intravenous was no longer a matter of isolating a vein, applying the tourniquet, puncturing through the skin, and feeling the pop as I advanced through the vein wall. Seeing the flash of blood up the cathalon tubing and then connecting the I.V. solution--the familiar sign of success was replaced with apprehension and fear. Every step of the procedure seemed new and strange--the latex gloves dulled my sense of touch--the blood flash in the tubing conjured up images of taunting the devil, and while attempting to tape the needle in place I was all thumbs as the tape stuck first to one finger on the glove and then another, the needle jiggled--the whole process seemed impossible.

The conversation that accompanied this scene was also stilted. I was so preoccupied with attempting to cover up my horrified, gut twisting panic that I played every comment over in my mind several times before saying it. I explained to him I had read extensively about HIV, but he was the first person I had met, I then said, "I am so sorry." These words stuck in my mind. I was sincere. I was sorry *for him, the fact that in a rural area like this he would be several persons' first contact with the virus, sorry about his prognosis, and sorry that HIV was now part of my professional reality.*

I worked with several persons with HIV over the next few years. As a nurse working in Emergency and Intensive Care, I mainly interacted with young men in acute medical crisis related to Pneumocystis Carinii Pneumonia (P.C.P.). These people required aggressive treatment to stabilize this life-threatening condition. Once they were stabilized, they were discharged to a medical unit or home to convalesce. I was also responsible for organizing the first out-patient treatment of pentamidine, a prophylactic drug treatment to manage P.C.P. infection. This introduced me to a different group of HIV/AIDS suffers, men who lived independently with the disease but required outpatient services. These men were not acutely ill, so I became familiar with a new aspect of life with HIV.

I adapted to universal precautions, refining my sense of touch to skillfully insert an I.V. distanced by the barrier of latex gloves. I could intellectualize and rationalize that I was at minimal risk of contracting this virus from the persons who had been tested and were known to be HIV positive, and the greater risk was associated with the general patient population whose HIV status was unknown. However, every time I worked directly with a person known to be HIV positive I felt emotionally more vulnerable and "at risk." On those occasions I would shower as soon as I came home and immediately wash my uniform. This was more of a symbolic act of separating the risk of work from my children and my home than an expression of disrespect or fear of the people I nursed.

In spite of all this, I retained the naive notion that HIV/AIDS would remain only as a fascinating academic and professional interest. I was particularly interested in the issues connected with a contractible, incurable disease weaving and molding a space into our present model of health care. Our medical model approach to illness treatment was dominated with a "conquer and cure" philosophy. Many new issues accompanied the infiltration of HIV into the illness care system.

This contractible, fatal, invisible virus had captured widespread public attention through the media. The naive and hopeful assumption that doctors and medicine could cure all ills had to be re-examined. People were fearful as they speculate about the mystery and power of this virus over the forces of established approaches to cure.

Health care professionals now had to establish alternate relationships. The new relationships focused on people infected with HIV and with the general public in emphasizing health promotion and education activities aimed at preventing the spread of the virus. The "conquer and cure" approach now had to share the limelight with a prevention, management and care philosophy.

Being successful in managing this virus required self-care and active involvement of the infected person. Self-care required the person to be knowledgeable about the disease and to develop a new sensitivity to how this virus expressed itself in his/her body. Medical expertise is an essential, valuable aspect of managing HIV, and develops into a respectful partnership with the infected person.

Nutrition, fitness, rest, stress reduction, and nurturing inner strength round out the self-care circle.

Remote to Heart Center:

Early in 1989, the false reality of HIV/AIDS remaining as a remote academic and professional concern shattered. The virus had been continually weaving its way into the personal aspects of my life. I now had friends and acquaintances who tested positive. In April 1989, my world view changed and fragmented. The story unfolded over several months as my brother became aware that he was at risk for HIV. It was like the wide angle lens of a camera slowly adjusting the scope until the picture was clearly narrowing to focus on some questions with which he could no longer avoid dealing.

Wayne had a great distrust in the confidentiality of the HIV testing system in Alberta, so his first major decision was to have the testing done at the Hassle-Free Clinic in Toronto. He had a conference to attend in Toronto so the blood was drawn at that time. The Hassle-Free clinic was one of the few places which allowed patients to phone back and give their code number to receive the test results over the phone. The actual test had been preceded by lengthy discussions about the implications of the test and what the results could mean.

Wayne and I had discussed several responses associated with a negative or a positive result. Nothing had prepared me for the impact of his words; with hesitation he confided, "*I'm positive.*" My overwhelming embodied response was one of fear, panic and anxiety. I was jolted into coming face-to-face with the fragile nature of life. I was acutely aware of how little my professional knowledge helped at this time. I wanted to set up barricades and protect him from any harm. In actual fact, I wanted to freeze time. As the virus burrowed into the most intimate depths of my heart, my consciousness was now shaded by a new reality, life with reference to dying.

Wayne's elaborate plans to have the testing performed confidentially seemed like a cruel joke because the positive results necessitated medical attention. First of all, medical intervention was necessary to determine the state of his immune system. Blood tests were required to measure T-cells, a vital part of the immune system effected by HIV. I hovered close in a pathetic, powerless manner while Wayne worked out what these results meant to him. Despite my previous knowledge and experience to me, the results meant death. In my panic and anxious state I was convinced he would vanish; my life was out of control. Wayne did not feel any different, and thus he constructed plans for living fully.

This moment had another significance. *'This has to be a secret;'* Wayne whispered. With those words he surrounded me with a lead barricade of secrecy. In the intervening five years, I have learned living with a secret drains the human spirit and depletes creative life energy. I was living with the unspoken question, "What is the experience and meaning of living with HIV?" This question has begun to orientate and to challenge me to explore every aspect of what it means to be human in this world. Protecting Wayne's secret became my secret, it also allowed me a watchfulness and quiet space as I reflected on the effect HIV people had on society and the impact society had on people who were HIV positive. My sensitivity to this marginal and silenced group increased.

Private Silence: Public Connection

Just at the point when the effect of the virus had circled in and found a home in my heart, the promise of secrecy silenced me from sharing this sorrow with the people who had been my support system. This support system was my core group of friends; previously we shared all joys and sorrows. Each time I met them, the secret echoed and rebounded in my mind as I sought desperately an avenue of expression. In the absence of their love and support, I felt alone and powerless. I also distanced my heartache from myself and in this absence I was hollow and hopeless. I attempted to construct some personal understanding of HIV/AIDS and to fill the emptiness; I became involved in the public realm.

The public forum I consciously selected was the Lethbridge AIDS Connection (LAC), where I became a board member. In this position, I had connection with political and community resources. This gave me a feeling that I was doing something to react against HIV. This public involvement provided me with an avenue to be with other persons and families who were affected. At the same time, I struggled to re-establish my internal dialogue which I needed to make sense of this experience. To re-establish inner meaning, I had to accept living with grey, unresolvable uncertainty as all my previous assumptions about life were questioned. I did not have a clear idea of what I was reacting against, but my private silence was suffocating me; I gasped for breath through public voice.

As chairperson of LAC, I was also a member of the Alberta Community Council for AIDS (ACCA) so I was able to collaborate with all the other community-based groups as well as the Alberta provincial government members of the AIDS team. My involvement in ACCA fed me continuous and valuable information on the social, economic, education, and health care concerns. I experienced collective political action and the process of lobbying for collective rights. The group lobbied to have: drug trials available to all HIV persons throughout the province, community education programs, pre- and post-test counselling, and financial and emotional support services. I continued the silence of my personal involvement with the issues, and when I spoke with passion and commitment I am sure others found my apparent detachment confusing and difficult to interpret. I know from my inside perspective I was confused--I felt I had no right to breach the secrecy-- and I housed this heartache and grief with no resolution.

To my close friends, I spoke in a riddled detached voice about my involvement with the LAC and ACCA. I had disguised my involvement as professional interest, a credible facade given my past work as a sexual health counsellor. The charade perpetuated a contradictory duality of public activist versus personal paralysis. I had found a public voice but was choked with personal silence.

In 1992, I attended the Canadian AIDS Society (CAS) meeting in Halifax. This national meeting expanded my awareness of national planning strategies. The dedication and commitment of the participants illustrated a essential characteristic of a Primary Health Care (PHC) model. The philosophy of PHC reflects the belief that people affected by a particular circumstance should have input to assess, plan and implement the use of health resources to meet their needs. There was true grass-root's involvement as the members of the CAS debated, discussed, prioritized and organized to make their need for services and treatment known to the federal government. The people living with HIV/AIDS in Canada were well represented as 30% of the participants were HIV positive. This large meeting reinforced for me the idea that the "personal is political." What affects an individual circles in and out to influence families, groups, populations, and countries but national human rights are only as strong as the amount of freedom, dignity and respect experienced by any individual. At this national conference, I had the opportunity to talk with HIV positive men and women from across Canada. Their stories made me realize that all persons, besides being infected with HIV, were also confronted with the social stigma and marginalized status that comes with the disease. HIV confronts our society with the topics that are most silenced: homosexuality, sexual behaviors and death.

I attended more conferences during the subsequent two years which contributed to my understanding of the complexity of the AIDS issues. In February 1992, The University of Lethbridge hosted a conference on grief and bereavement associated with HIV/AIDS. Participating in this event, I gained an awareness of the complexity and complication of the unique experience of multiple loss and cumulative grief, particularly in relation to AIDS.

The information presented at the conference stressed how inadequate the traditional stage model theories of grief for addressing the devastating multiple losses associated with HIV. The traditional models assume the individual is responding to a single loss, and then engages in a sequential progression of stages in coming to an understanding of the loss. Over the years, many stage models have been developed to outline the process of grief: Freud, 1917; Fininchel, 1945; Pollock, 1961; Kubler-Ross, 1969; Bouilloy, 1980; and Sander, 1989 (Sewell, Bramlette, Guedner, Gertzmachen, & Martin, 1991, p. 901). Elizabeth Kubler-Ross' (1969) theory is the classic example of this type of model. The stages as outlined in her book, Death and Dying are: (1) denial and isolation, (2) anger, (3) bargaining, (4) depression, and (5) acceptance. Kubler-Ross is a pioneer in breaking the silence that surrounds death and grieving. Society in general, and health care professionals in specific, ignore, deny, and silence the final transition of life - death. Vichor Frankl's (1959) book Man's Search for Meaning, in which he gives his account of the losses and magnitude of suffering in a concentration camp parallels the horrendous suffering and multiple losses associated with HIV/AIDS.

On a positive note, the conference helped me understand the emotional turbulence I was experiencing, and helped me name my feelings as grief. Grief truly is the holistic response I was living through; as I adjusted to the emotional, physical, intellectual, behavioral, and spiritual process of loss associated with someone or something of value. In the past 18 months, I had lost a partner through a divorced ending a 17 year marriage; separated from two of my children; lost the fantasy and hope of "traditional" family; my brother's change in health; lost an aunt and uncle lost to long battles with cancer; the family home; employment; Yale and Tim's deaths from AIDS, . . . Ironically, I was studying multiple loss and grief as a professional and intellectual phenomenon but could not recognize it at work in my own life. The insight I acquired by participating in the conference was grief is not a distant stranger to me, but grief is a mysterious unpredictable companion, a force that shades my life, rules my energy, and in my weaker moments directs my life.

Next, Wayne and I attended the 5th Annual British Columbia HIV/AIDS Conference in Vancouver in October, 1992. This was the first time Wayne and I had attended a health care conference together; it was a strange experience. We both felt the more knowledge we had about HIV, the better we could manage the transitions of the disease in Wayne's body. We attended several of the clinical medicine sessions on a range of topics such as: retroviral drug studies, pulmonary effects, gastro-intestinal pathology, cytomegalo virus, retinopathy and dementia. The cold, detached, scientific medical sessions left me feeling numb. While the information was useful, in some ways it stifled conversation between Wayne and myself, as we struggled to put our thoughts and feelings into words in the context of the conference environment. Being there together was symbolic of how we, as brother and sister, had united our forces against the HIV.

More important than the substantive context of the conference was the time Wayne and I spent together. It was my first time in Vancouver, so Wayne took great delight in sharing his favorite parts of the city. We stayed at the Sylvia Hotel where we had a spectacular view of the English Bay. Ironically, our walks on the sea wall and bicycle ride around Stanley Park were of greater healing than the information at the conference.

The keynote speaker at the Vancouver conference was Dr. Peter Jepson-Young. It was a powerful experience to witness the wise, clear and articulate words that flowed from this person who sat before me; wheelchair based, shrunken, and prematurely aged. Dr. Peter had AIDS. He had become a household name in British Columbia, as well as across the country,as a result of the open, honest, direct television series he documented to highlight the process of his disease. Dr. Peter was a family physician in Vancouver and his story highlighted and captured the dynamic, constantly changing invasion of this syndrome. He represented the contradiction of AIDS; the youthful spirit cloaked in death. Hearing him speak was a deeply humbling experience. It made me realize the bravery and courage displayed by each and every person who lives with HIV/AIDS at this time in history.

This series of events and public activities gave me a connection to the issues and opportunity to listen to the personal stories of people living with HIV. I consider these stories as precious gifts which have helped me to reframe my own story as a person greatly affected by HIV. I will never know exactly what it is like to live with HIV/AIDS, but I have a desire to explore, hear and understand. I am close to the experience of HIV/AIDS by loving a person who is infected. I travel the journey with this person, but HIV is not physically in my body. Instead, HIV resides in my heart and my soul.

To this point I had not blended my public activities and professional interest with my graduate work. I was stretched and distracted by the expectation of my work, graduate school, AIDS activism, and my personal concerns for Wayne and my immediate family. Each domain competed for a share of my limited emotional and intellectual resources. The fragmentation scattered and dwindled my energy. A transition in my philosophy of education helped to establish congruence in my life. This philosophical shift parallels the theme that the personal is political; I believe education must be personally relevant. While reading van Manen's (1990) book, Researching Lived Experience , the "augh haw" response of clarity and insight happened when I read:

> Things turn very fuzzy just when they seemed to become so clear. To do a phenomenological study of any topic, therefore, it is not enough to simple recall experiences I or others may have had with respect to a particular phenomenon. Instead, I must recall the experience in such a way that the essential aspects, the meaning structures of this experience as lived through are brought back, as it were, and in such a way that we recognize this description as a possible experience, which means as a possible interpretation of that experience. This then is the task of phenomenological research and writing: to construct a possible interpretation of the nature of a certain human experience. In order to make a beginning, the phenomenologist must ask: what human experience do I feel called upon to make topical for my investigation? (p. 41)

Finally, with some relief, intuitively I knew this was the right way to proceed. I am called upon to investigate "What is the experience of living with HIV/AIDS?" This question had served as an orientation point for me, but now the congruence of the personal, public and academic focussed my energy and consciousness. I phoned Wayne and requested his participation in my study. "I am changing my thesis," I told him. "This is important writing and I need to bring my deep interest in HIV/AIDS from the back lobe of my brain to the front lobe and focus my interest. Wayne was interested in this transition and offered to anonymously share his insights.

Connecting Scripts

The quest associated with understanding the question lead me to explore the stories of persons living with HIV/AIDS. The stories of the people I talked with became a way of unlocking my personal silence and I became their ventriloquist, giving them a safe public voice, and they became the ventriloquist of my private voice.

Wayne, my brother, and I have a rich friendship which permeates beyond the boundary of brother/sister blood bonds. We are soul-mates. Our lives contrast: he is organized, I am disorganized; he is urban, I am rural; he has travelled world-wide, I know intimate details of my small local area. These differences round out the unexplored terrains of each other's lives. We share a sharp wit and sense of humor that escalates with the synergy of our connection. We speak in half thoughts, but understand each other fully. The most precious gift we share is the deep respect for each other and we value the magical force between us.

Wayne is 40 years old, a dynamic educator who shares with me the joys, sorrows and perceptions of his world. Through his diary while living with the advanced HIV/AIDS and our conversations his voice has given me insights into the life of a person living with HIV. His story describes the ever-changing experience and unpredictable process of HIV.

The threads of Wayne's words and my words are woven together to create the themes of this work. The story has taken many twists as we have worked to evolve from detached anonymous voices to unveiled honesty.

The first manuscript I wrote on the topic of HIV was a disaster. The content was based on the empirical research literature on AIDS with smattering of confidential quotes. The flow was fragmented and the tone was a weird mix of formal expository writing and brief glimpses of the personal connections. The paper spoke in half-truths and riddled detachment. The piece existed as a text but the people and texture of their lives did not come to life in that text. Reading the manuscript, Wayne reached the point of wanting to cast aside his mask of anonymity and to reclaim his voice. Thus, the first tinges of authenticity in the work was announced.

> *I was aware that my journal would be made public from the onset. At first, it was one method for me to continue some intellectual involvement--contributing to the completion of Joan's graduate work. As the diary unfolded it also became clear that it was a vehicle to reach a broader audience. People need some personal experience or have to relate to personal experience to develop a framework to comprehend the complexity of*

> *HIV/AIDS. It is truly unlike any other disease. It is through my diary that I hope other people can gain a perspective of the death and severity that HIV has on the personal lives of individuals, friends, families, and entire communities. . . gay.*
>
> *Once the diagnosis has been made everything changes for that person. Health care workers have to be aware that they are treating more than a series of symptoms. Perhaps through personal experiences, such as those expressed in my diary, they can better appreciate the complex issues surrounding the disease. There is a great deal of silence and secrecy that surrounds HIV. In the past two years I've managed to break down many barriers that propagate this 'suffering in silence' attitude. I've educated friends and family and become politically active in a very public way. Having the journal used in a public way [in Joan's project] is another step toward liberating myself and, in an abstract way, liberating the disease from the fear which surrounds it. It also provides a way to reach a greater number of people than I originally deemed possible. Fear is generated through lack of experience and education. I hope the journal will provide at least a snapshot of the horrendous ramifications of this disease, and encourage people to further explore and build their understanding and their compassion. (Wayne, July 23, 1993)*

It is his proud sense of hope and autonomy that comforts my heart, and allows me to now re-write this project with authenticity. For a long time I struggled with the idea that it is not my story to tell, and that I might be one more opportunistic parasite hitching a ride on the AIDS bandwagon. I was aware of the uniqueness of my relationship with Wayne and our understanding of HIV. However, I also felt that we are part of a larger picture. Our experience exists only as part of the broader socio-economic, political, historical landscape. For this reason, I allowed my exploration of the terrain of AIDS to broaden. I began to converse with others infected with HIV.

The conversation happened as one-on-one dialogue, and in small focus group discussions. I had talked with a variety of persons affected: a married woman who's husband had an extra-marital affair which lead to both of them contracting the virus; a woman who's husband was the first hemophiliac to die from AIDS; a rural farmer in his remote country home; mothers and sisters who supported their sons and brothers; and groups of gay men in places they felt safe to gather. I had the privilege of entering peoples' homes and listening to their stories. My contributions to the verbal dialogue was minimal, but my sincere will to be genuinely present filled the space between myself and others. I had a need for silence and they had a heartfelt desire to talk safely with someone. Words fail to describe the gift of connection and presence that happened in these conversations. I began each meeting with an open, broad invitation, much like: "The questions that wakes me up at night and lingers in the back of my mind all day is 'What is the meaning and experience of living with HIV/AIDS?' I'd like to hear what you can tell me about this."

The conversation unfolded. Occasionally, I would give verbal cues inviting the person to explore particular aspects of the topic touched on earlier in the conversation. There were often periods of reflective silence, filled with emotion and reframing insights.

I was honest with the participants and acknowledged my own deep roots and connection to the question. At times I would share personal stories, and I relied on my intuitive response to guide me with the appropriateness of such comments. My intent was to listen, but at some moments speaking seemed inevitable and appropriate. This reciprocity and blending of stories and experience facilitated my understanding of the experience of living with HIV.

My voice to the question "What is the experience of living with HIV/AIDS?", is a culmination of weaving the stories, spinning the threads from conferences, community agencies, lectures, documentaries, conversations, group discussions, and individual and personal reflection. Writing I found myself working like a conductor. I have been given the precious gift of the opportunity to orchestrate and coordinate the rich, rhythmical, diverse voices. Initially, I waited for articulate, decisive, logical words to flow, and to create a smooth rational understanding of the question. When that clear tune never happened, I proceeded to write with the unpredictable, erratic beat of jazz. The unfolding pattern of jazz components began to reveal some of the dynamic, elusive nature of living with HIV/AIDS.

I invite you, the reader, to enter the lyrics,and to reflect and respond. There is no capturing the answer; there is only the ongoing nurturing of insights and understanding which is contracted by continuing the dialogue. Welcome to my interpretation of the question "What is the experience of living with HIV" and I invite the reader to interact with the themes, threads and rhythm of a new jazz.

Multiple Loss

Multiple loss has been a resounding theme throughout the literature, conversations, diaries, and impacts on every aspect of a life infected with HIV/AIDS. The losses surface in both physical and abstract ways. "Most people with HIV experience multiple losses, including friendship, family, employment and hope for a long life" (Nokes & Craven, 1991, p. 177).

> They often experience social stigma from family and friends, loss of lovers and significant other, loss of occupational and financial resources, denial of shelter and health care, and profound prejudice from society. In addition, abstinence from sexual contact and diminished social contacts. Loss of significant others and friends may occur from actual death of lovers and friends from AIDS. (McGough, 1990)

These authors state in an antiseptic way the quantitative loss associated with HIV/AIDS. But they beg the questions: What does loss of employment mean? What does it mean to have several close friends die in one year? What is it like to live fearful, hopeless, and powerless?

Loss of Employment

Wayne started his diaries at the point where his health complications and chronic fatigue no longer allowed him the energy to continue his loved practice of public school teaching. To stop working was to acknowledge that this virus had permeated an intrinsic dimension of his being. Once again he was being forced to accept a loss long before a "natural" time.

Many of the young men I talked with expressed an entrenched work ethic. Terminating work prematurely as the disease sucks vital energy, forces these same young men to redefine themselves and their social roles. Time and energy are scarce resources as they re-evaluate their space in society. Loss of work has a domino effect. That first little tile is knocked over and the chain reaction begins. The tiles topple one after another: loss of connection with children, interactions with colleagues, the rhythm of a work day, the school year, financial security, the forum for self expression, group membership, social rewards, and purpose for living.

Leaving work is not emotionally neutral. Leaving work is a transition shaded with hope for the future, passion for the present, roots in the past.

> *After months of deliberation I've discovered there isn't an ideal or right time to leave. It's important to make the decision and stick with it, and get on with the next phase of your life. Now that I've decided to leave, many things seem clearer for me. One thing was that many barriers to quit work were external - what will I do? What will people say? What will my new role be in life? It was when I started to let go of the external factors, and started to listen to my body that the decision became clear. NOW it's time to get on with it.*
>
> *I know there are many hurdles to go but at least the race has started. Leaving work forced other issues to the forefront - telling my friends, parents, and basically coming out again.*
>
> *My whole body was screaming, 'now is the time.' I expected resistance from the doctor - when he agreed with me I was surprised. I phoned the office to say I would be going on medical leave. This was a way*

> *of jelling the decision - almost as though I didn't trust myself, or would change my mind because of guilt or duty by money. . . . I cleared out my office at my base school. The day was quite an emotional roller coaster . . . . I experienced a whole gamut of emotions. At one point close to tears, another I was melancholy and just minutes later I had a huge 'fuck you' smile on my face.*
>
> *I realized I'd been taking steps to leave for a long time. Last year I left my busy job as a consultant. . . .*
>
> *The whole process had been a gradual letting go of work and gradual building of the need to care for myself and nurture my needs. (Wayne, March 13, 1992)*

Wayne chose to clean out his office at a time when the school was empty.

> *No kids, no teachers, no support staff, no one. The only sound was a local radio station pumping country tunes into the corridors of a three story sandstone school named after a dead king. (Wayne, March 17, 1992)*

The transition had happened. He now saw himself as an outsider to the school system. On March 19th, the staff had a 'Get Well' wine and cheese party. He wrote, *'I was nervous driving to the school and didn't really know what to expect - everything had changed in my mind. It was like I was entering the school for the first time.'*

Wayne was saddened by hearing how much the ESL students missed him. He wrote about the pull he felt. He no longer had the energy to teach and nurture those children but he felt guilt about directing his limited energy toward nurturing himself. In leaving the farewell gathering, an internal emotional storm started brewing. *'The grieving process is much stronger than I expected. I shouldn't be surprised - I've been teaching and learning for over 16 years and I loved the job. I also have* *pride in the fact that I was good at it.'* How does a professional person for whom his work is essential to his being re-establish the meaning of self within the absence of work?

Wayne knew his "sick leave" was a permanent move. His employment had ended, but the loss of employment does not extinguish the consciousness, and passion of a life-long career. Leaving work ended the external expression of his career, challenged his self-worth and yet provided an enormous sense of relief. As a gay teacher he had maintained a dual existence and had carefully divided the professional and personal. As a HIV positive gay teacher, he felt vulnerable. He embodied and represented the aspects of life which society chooses to silence: homosexuality and death.

> *It's strange how we wouldn't hesitate to tell people we have a cold, cancer or a migraine headache and yet disclosing you have HIV conjures up fear and loathing. HIV is a disease cloaked in fear and evil to the general public. Cancer patients are considered courageous when they have chemotherapy and yet HIV sufferers are shunned. (Wayne, March 13, 1992)*
>
> *As a gay teacher I was very guarded, rumors start quickly and parents become judge and jury. . . . Knowledge and facts have little to do about gossip. I was always paranoid as a gay teacher and this reached new peaks in April, 1989 when I tested positive. Regardless of how brilliant or popular you are as a professional in the classroom this secret would make your life hell. . . . Now that I see how the provincial government is reacting to giving gays no protection with human rights legislation my paranoia and fears are well founded. (Wayne, January 9, 1993)*

The tremendous relief Wayne felt in ending work before he was found out to be a gay, HIV positive teacher reflects the discrimination entrenched in our institutions. Wayne was not alone; many of the other men I talked with had the same fear of disclosure. If their employers discovered they were HIV positive, they would be dismissed immediately. Therefore, keeping the secret of HIV status is not paranoia, but is essential for survival at work.

Walter worked as a laborer in a small rural business. He had no buffer zone in the form of a labor organization between himself and the employer. Walter's employer did not know he was gay, but the employer's attitude toward gays was made obvious with frequent jokes about "fags." Once his HIV positive status was known Walter knew he would receive no support from the people at work.

> *Some people I tell, some people I don't want to say anything to. It's like my employer, where I work they have no idea. All I told them was that I had cancer and that I was taking time off, and I was on my disability and what not. They kept saying, "What kind is it? What kind is it?" And I just said, "Cancer, leave it alone." Because it was just their attitude would not have been good, I would have lost my job in a second. I would have been gone, I would have been out of there so fast.*
>
> *(Walter, 1992, p. 2)*

Secrecy and silence serves to protect the infected person from certain negative ramifications such as job loss. However, part of the price of this protection is that persons with HIV remain an invisible part of the workforce in mainstream society.

To change social attitudes we need people who will break the silence and force the discussion. But what are the personal costs for doing so? At the Vancouver HIV Conference (1992) a familiar story is told.

> *I am a Chartered Accountant and was the vice-president of a financial company. I had just transferred from Toronto to Vancouver and I was such an important man to the company they wanted me insured for lots of money. I am a married man with children and never thought anything of the regular life insurance health screening. The results of the test were positive and the life insurance company accidently let this slip. Suddenly, I was not so valuable to them anymore. I was offered a settlement and terminated. (Barry, 1992)*

At the 1992 Vancouver HIV Conference the participants on the panel had been dismissed from work because of their HIV status. They emphasized the difficulty of the choice: Do you accept the payoff? Do you endure the stress of a legal battle and fight for your right to work? These battles have a high cost to the individual living with HIV/AIDS: physical health, social stigma, and economic burden. McGough (1990) has documented the impact of stress on the immune system. The stress of these legal battles speed up the HIV/AIDS process and ultimately leads to an earlier death. Although these battles appear to be between individual employees and employers, they reflect the issues at work in the society at large.

There is a need for collective action to create social change. The workplace presently is neither just nor fair for all persons, as the legislation protecting workers assume heterosexuality, and a patriarchal family structure. Human rights legislation to protect persons from discrimination based on sexual orientation would be an important beginning step to secure basic rights. Changes in attitude are difficult to achieve, but are necessary to dispel the myths about homosexuality and decrease the fear associated with HIV/AIDS. Homosexuals have invested a great deal of energy into remaining invisible in the work place. Given a culture based on fear and secrecy, how do gay men then find the power and courage to openly lobby for the same rights as any other person, in a society which would prefer they remain silent?

Dr. Peter, at the Vancouver Conference, Wayne, in his diary, and Walter, in conversation, all describe revising their sense of self, a process necessitated by having to live a life without the structure and rewards of paid work. All of them had always lived with a drive to be productive with their time. Dr. Peter produced the CBC documentary series. Wayne, once his long-term disability was approved, found alternate ways to continue to be an educator. He continued the diaries, became involved in political issues related to human rights and wrote the correspondence for a gay and lesbian group. Walter, also after his disability insurance started, became involved in public education and support work. Formal employment may end, but their need to be productive and contribute to society goes far beyond the paid workforce.

Social Loss

Loss of employment is only one of the multitude of losses experienced. The social losses are devastating as many gay men witnessed several friends die from HIV in one year. A memorial service was held at the Canadian AIDS Society, 1992, Halifax meeting. I was numbed as the long list of names of persons who had died in the past year was read and the names continue to echo in my mind. Wayne's diaries document the gradual erosion of the number of persons in his support network, and onslaught of personal losses.

> *It's difficult to grasp the dynamics of a disease which affects so many close friends. The grieving process never has an opportunity to go through all the phases. Before you complete the process for one person, another friend or acquaintance is seriously ill and has died. It just goes on and on. . . . Everyone wants to personalize their reaction. This has taught me a great deal about the importance of listening to what people say and what their body language says. (Wayne, March 30, 1992)*

There is unique suffering associated with HIV. While dying is universal, people infected with HIV suffer uniquely as they witness fellow victims die. The disease intertwines a double sorrow: first they connect, support and nurture their friends who are dying; second, they recognize this as a possible road map for their own journey towards death. Each friend's story is a mirror. Each person's story is unique, but to compare is inevitable and serves as a constant reminder of a horrifying future. Each friend's death further erodes their dream of a long life, the dream that "*Once upon a time, a magic cure is found and life returns to a happy ever after state.'*

> *I knew Yale would die very soon, but the next day? Yale's death hit very hard, not just at the time, but for months after. I still think of him everyday. . . .He was the first person to die of AIDS in my inner circle. For years we all had Christmas, Thanksgiving, Easter. . . together. Yale's death made the disease concrete and dangerous. We watched the disintegration of his young body. . . . I knew death was inevitable for those of us with the HIV virus.*

> *Yale's death ended the fantasy that somehow the rest of us would be alright and would manage to escape illness. (Wayne, September 29, 1992)*

Infected bodies are hosts to a silent, dominating virus that effects social, particularly sexual, interactions within the gay community. Relationships are changed by the disease and individuals are forced into renegotiating the terms their of sexuality and the terms of future sexual relations.

Mainstream society stereotypes and defines gay culture by sexual acts, and is locked in this narrow genital understanding of homosexuality. While gay life once represented freedom of sexual expression, HIV and safer sex practices have introduced new restrictions on sexual actions. Some of the restrictions have prompted a commitment to monogamous partnerships.

> *Sex has always been very important to gay men. Gay men are frequently (or used to be) promiscuous. There are lots of reasons for this. Unlike heterosexual sex there was no fear of pregnancy. Men are raised to feel it is acceptable for them to have sex with many partners (but the bride should be a virgin, the groom experienced). Men don't think of sex and love as a necessary couple, sex is a physical pleasure for men that doesn't need an emotional tie. . . .*
>
> *Sex allowed them to be gay in an open way. In the privacy of bedrooms they were allowed to feel the freedom of being gay. Sex becomes a feeling of power and freedom for the gay individual closeted within. . . This was one of the few times gay people could sense freedom. Sex gave a sense of freedom, and freedom can be a very intoxicating emotion - especially if a person feels powerless in society. (Wayne, January 14, 1993)*

When HIV became part of the equation new dimensions to sexuality unfolded, and the cost of sexual freedom escalated. Wayne has been gifted with love and commitment in his nurtured fifteen year relationship with his partner John.

> *I feel very fortunate to have John now. If ever there was a time to have a lover and companion it's now when I have a terminal illness. I really missed John when he was in Newfoundland visiting his mom. Something was really missing from my life. We talk all the time on the phone and spend a great deal of time together. There was a real personal void for me when he was away. (Wayne, February 16, 1993)*

Not all gay men are that fortunate. Walter talks about longing to have a partner and the loneliness of being an aging gay HIV positive man.

> *People used to base everything on that (sex), especially in the gay world. I also want companionship, someone to talk to, somebody to hug in the morning, just to be there. . . . I pray every night that some how, some day, I will have somebody, and its very, very difficult especially alone here. (Walter, p. 7)*

In his isolated, rural home and coupled with silence about his sexual orientations, the possibilities of finding a loving companion seems like a distant dream.

Brian, a young student I talked with, feels extremely lucky to be in a relationship. Brian was HIV positive when he met his partner 18 months ago, and despite the complexities he now has live-in companionship. He talks about the frustration he feels when people only see his relationship with his partner in terms of a sexual act.

> *What I do behind closed doors is my business, what other people do behind closed doors is their business. But they [public and media] have made it become an issue. They don't look at the relationship between two people, being the same for homosexuals as it is for heterosexuals. That love is the same, it's strong and important. (Brian, November 1, 1993)*

Each of these people infected with HIV/AIDS have helped me to be more open and receptive and to fully acknowledge the loving qualities and richness of gay relationships. I attended a dinner party to celebrate Wayne and John's fifteenth year of meeting. At this celebration, I experienced the magical, mystical, interactive force of love, respect and valuing between these two men. It made me rethink and challenge some of my previous assumptions. Despite my long standing "liberal" attitude, I realized this was the beginning of a deeper understanding of the authenticity and legitimacy of Wayne and John's relationship. My children had always called John "Uncle," but that title took on new meaning as I realized John is my family, too.

Loss of the Secret

Secrets are no strangers to gays; for years they have masked their sexual orientation. HIV becomes an additional secret to harbor. For me, keeping Wayne's HIV status a secret took constant conscious effort and consumed tremendous energy. The secret created "double talk". I felt I was having stereo sound playing in my mind. The confusion was created as one speaker blasts out the dialogue of life as it rolls along, and the other speaker keeps replaying the monologue of the secret. Sometimes the sounds are synchronous, but at other times I am distracted and have a 30 second sound delay. This double talk is exhausting.

My consciousness of activities of daily life are altered. The routines remain the same: I get out of bed, make lunches for my children, nag them to get up, and share meals with them; at the university I teach and interact with colleagues and students. But despite the familiar routine, I view life differently. The daily concerns of my mind are often in conflict and competition with the concerns of my heart. As I teach contemporary issues to nursing students and discuss oppressed group behavior, political actions and pressure group formation, the words I speak highlight the role of nurses in traditional health care. But the back lobe of my mind is popping with ideas and application of this information as it relates to my work with AIDS Connection and my life with Wayne.

The double talk in keeping the secret from the rest of my family was awkward. Mom phoned in May 27, 1992 at 8:30 a.m. to tell me Aunt Lorraine had died. She kept saying, "I also phoned to leave a message on Wayne's machine and was surprised when he answered the phone. He should have been at work. Joan, I know there is something wrong, as a mother I know. Is Wayne okay?" This is not the first time she had asked, but her voice had that quality of certainty of knowing Wayne was not okay. I lied; I covered for Wayne; I minimized her intuitive knowing. My loyalties were with Wayne, as I believed this was his secret to tell. But as a mother myself I felt I had betrayed my own mother. That the cost of keeping the secret was alienation became increasingly clear to me.

To many gay people, the secret of sexual orientation and HIV status cannot be separated, and the ability to maintain the secret becomes an icon of power and control. Living with HIV, the individual is confronted with constant ongoing change in all aspects of life. While many changes are beyond personal control, the individual is still the gatekeeper of who is told the secret. They channel an incredible amount of energy and thought into who, how, why and when people are told the secret of both the disease and their sexual orientations.

Each individual constructs their own reasons for telling or not telling people. There were many reasons for not telling. Wayne, Walter and Brian did not want to burden those close to them with the pain of knowing. Walter talked about not wanting to hurt his mother. Brian enjoyed his family relationship as it is and did not want to alter those dynamics. To Wayne, independence and autonomy were the highest priority of his life, and he did not want people treating him as if he were ill and dependent.

Walter was sick and weak before he was diagnosed HIV positive. He had already left work on medical leave and describes how he decided to tell his parents after returning from Calgary and the Southern Alberta Clinic.

> *I told my parents and that had to be the hardest thing in my life that I ever had to do. . . I said "I'm very sick," and my mom said, "I know. . . . You have slowed down, you let your business go. . . ." Dad doesn't seem ready to understand. . . It is really hard on her (mother). It was really hard on her that day, on both of them that day I told them because my mom just broke*

> *down on me. I mean your son comes and tells you that he is going to die. (Walter, March, 1993).*

Brian, on most days, still feels healthy. He has a supportive family and does not feel the need to tell them now.

> *I want the lines of communication left open, I want, it's almost a facade but I want things to remain the same within the family. . . . I don't want complications of the relationship. I also don't want the hassle of trying to educate, the hassle of trying to cope with their stress along with my own. I feel not telling them is in a way protecting them. It's also protecting me, too, granted. . . I'm healthy and not telling them gives me a reason to remain healthy. Not telling keeps my life less complicated. I don't want them calling me and saying, "How are you?" . . . Not telling helps me remain that complete person right now. . . . When I need that compassion, when I need that emotion, I know it will be there. I enjoy my family and want to remain in that happiness. (Brian, November 1, 1993)*

Wayne spent months struggling with the decision of when and how to tell the rest of the family. Every conversation he and I had seemed to end with a discussion of the pros and cons of telling: who, when, where, and how should they be told. Like Brian, Wayne did not want any changes in how he was treated by the family. But not telling also has its emotional costs.

> *Dad and Mom called yesterday to wish me Happy Easter. I felt like a bit of a snake when I had to lie to them about work, holidays, etc... I continue to weigh the pros and cons about telling them or not telling them.... Next time they are in Alberta I'll tell them the news. (Wayne, April 21, 1992)*

Finally, they were told.

> *I was actually terrified of telling them. After we went to the funeral home (Aunt Lorraine) on Friday night was the designated time in my mind. We all sat down in the living room with drinks. My heart was pounding, palms wet, and voice cracking as I started, 'I have something to tell you. . . .' I remember the sequence but not the details. Mom cried and said how sorry she was for me. A huge weight was lifted from my shoulders. Part of the burden had been lifted. I felt love flow and knew I had done the right thing. . . . I know that they were still reeling from the news but I know we can get on with other things - healing things. (Wayne, June 9, 1992)*

To these men, to keep the secret represented a way of keeping the virus at a distance. Each had knowledge of the retrovirus present in his physical cells, but the presence of virus was not in his conversations, and interactions with others had been limited by the secret. His body is shaded by the virus, but his relationships are not, and the ability to maintain this secret signifies containing the actual virus.

There is an irony about the paradox of keeping or "coming out" with the secret. The secret is a cruel myth of control as over time the disease and the secret compete. Will the secret be told and come out about the disease? Or, will the disease come out and force the end of the secret?

Wayne's diaries reveal this "second coming out" process. In the previous year he had just had to deal with coming out about his sexuality. Then HIV forced a second coming out struggle. The second coming out also happened over a number of years: acknowledging the need for testing, planning the testing, dealing with the results, seeking medical help, visiting the clinic, telling professionals, commencing medication, experiencing the symptoms, controlling the secret. . . Slowly as the disease "outs" the secret there are very few people and details to tell.

The process of being "outed" by the disease happens in stages. At first, there are a large number of strangers who have access to the secret. After the HIV diagnosis, the first hurdle faced by many is the visit to the HIV Clinic. This visit becomes a forced public declaration and the secret is eroded by the initial screening and admission to the clinic. The nurse, doctor, social worker, psychiatrist, pharmacist, researcher are just a few of the "in the know" players added to infected HIV person's world. Ironically, this intimate knowledge that is shared with multiple professionals and strangers must at the same time be withheld from the intimate core of gay and straight friends and family.

Brian describes how commencing medication signifies letting go of the secret and acknowledging the force of the virus.

> *Well, it's been three years without any complications. I do take medications, the medication was the first hurdle or experience where you question your inner self. . . . Medication is probably the first thing that causes fear for the person because you realize that it [HIV] is something that does need attention, physicians attention, and it does affect you physically if you let it. . . blood has to be taken lots. . . . (Brian, November, 1993)*

Commencing medication necessitates lifestyle changes, as the anti-retroviral pills must be taken on a rigid six-hour schedule.

This requires sleep disruptions. DDI medication can not be taken with alcohol, and DDI must be taken two hours after food and two hours before the next meal. All these constraints require conscious commitment and adherence to a structured way of life. To HIV positive people the beeping of a wrist alarm does not mark time in a general way, but signifies specific meanings for time: it's time for medication; life is ticking away. To commence medication for HIV/AIDS is not a simple task like taking antibiotics for bronchitis, but a complicated ordeal.

Drugs like AZT and DDI are difficult to obtain. The anti-retroviral can only be prescribed by a few selected physicians; they are controlled by stringent drug company research trials; and they are dispensed only at a few designated pharmacies. Participating in drug studies requires travelling to the Southern Alberta Clinic in Calgary, and cooperating with the conditions of the study.

Drugs prescribed to slow HIV replication are toxic substances that have the potential to provoke debilitating side effects. Wayne describes the side effects of taking AZT as "learning to live with constant flu-like symptoms including nausea, diarrhea and stomach cramps." Peripheral neurological inflammation and pain necessitates stopping the drug periodically, only to resume it again.

The domino effect created by the decision to leave work also affects "coming out" and letting go of the secret. The balance of the scales shifts bringing less need to maintain silence. Another whole wave of strangers, such as insurance companies, government pension and social service personnel, become privy to a once closely held secret. Most individuals found the need to tell family members grow stronger at that time. Wayne reached the point where the burden of deception and lying about attending work seemed to outweigh the positive reasons for not telling the rest of the family.

The amount of time and energy put into the decision to tell or not tell becomes ridiculous rhetoric, representing the myth of personal control, as the virus progresses to a point that makes maintaining the secret impossible. Letting go of the secret is paralleled with a new sense of freedom as the infected person moves on to more collective public and political expression.

The reasons for perpetuating the secret are rooted in fears of death, sex and homophobic reactions. To tell the secret invites possible rejection by professionals, co-workers, family and/or friends, a reality many postpone facing as long as possible.

Loss of Safety

Kubler-Ross (1987), a noted author on death and dying issues, describes another challenge of HIV:

> Little did we know when we first started that all this was subtle preparation for a far greater tragedy that was still on the horizon: the pandemic of AIDS. It took twenty years for the American people to feel more comfortable talking about death, openly discussing the possible use of a hospice and/or palliative care unit for elderly parents. Now, millions of young people are faced with premature death, and the number of hospice and hospital beds available to them is far too small to accommodate their needs.
>
> Not only do people with AIDS have to go through the "stages of dying," they are faced with issues they would not

> have had to deal with to such an extent, in such massive numbers, and from every direction. AIDS has become our largest socio-political issue, a dividing line of religious groups, a battleground for ambitious medical researchers, and the biggest demonstrative of man's [sic] inhumanity to man [sic] - even far exceeding the treatment of leprosy patients in Damien's day. (p. 4)

Like leprosy, AIDS has a slow smoldering way of conquering the body, and presenting visual physical evidence of disease. In the past, lepers were separated in colonies and isolated from other people. This is not dissimilar to the treatment experienced by some of the first people hospitalized with AIDS. Early AIDS victims were placed on "strict isolation" in their rooms, fed off disposable dishes, and any skin contact, thus such traditional healing activities such as back rubs, was eliminated by the intrusion of latex gloves. Laws exist to enforce restrictions on sexual behavior and quarantine of HIV/AIDS patients was discussed in the mid 1980s. Leprosy and AIDS patients share a painful social alienation rooted in fear and discrimination. HIV/AIDS bears the additional burden of homophobia.

Homophobia is far more than the reaction of a heterosexual against homosexual. Heterosexism is the dominant norm used to construct and maintain our patriarchal society in which homosexism is devalued and considered an aberration and thus forced to the margin. Heterosexuals have become the dominant oppressor group, while homosexuals have become the oppressed group. To be oppressed means to be devalued and not allowed to fully and authentically contribute to society. Society values the qualities represented by heterosexuality. The oppressed group, in this case homosexuals, often takes on the values and norms of their oppressors, in order to gain recognition and value. Homophobic attitudes are not only external socio-political forces, but become internalized by the homosexuals as they learn to devalue themselves.

Homophobia and HIV perpetuate oppression. "All oppressed people suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts and feelings" (Young, 1990, p. 4). Young describes the injustice of oppression in five categories; exploitation, marginalization, powerlessness, cultural imperialism, and violence. In our capitalist society, the pharmaceutical companies exploit people with HIV. As documented above, the drugs are expensive economically, socially and for the well-being of infected people. The pharmaceutical companies reap power, status and wealth from the drug trials. Marginalization is a form of oppression where "a whole category of people is expelled from useful participation in social life and, thus, potentially subjected to material deprivation and even extermination" (Young, 1990, p. 53). Devaluing of homosexuals in a mainstream heterosexual society existed before HIV, and now HIV further marginalizes gay/lesbian people. The powerlessness of gays is experienced through their lack of authority, status and sense of self. This powerlessness is extenuated by HIV. Wayne talks about a constantly changing body and, thus, changing sense of self which accompanies the disease leading to a decrease in personal power. HIV and homosexuality are shaded by ever decreasing legal and social power. "Cultural imperialism means to render the particular perspective of one's own group invisible at the same time as they stereotype one's group and mark it out as the other" (Young, 1990, p. 59). Thus, we see gay men experience all the five faces of oppression Young cites, and with the onset of HIV/AIDS the faces only grow darker.

Homosexual cultural is the other in a heterosexual world . Violence exists as some "groups live with the knowledge that they must fear random, unprovoked attacks on their persons or property, which has no motive but to damage, humiliate or destroy the person" (Young, 1990, p. 61). Such violence is real and common in the life of gay men.

> *Yesterday I went to visit my friend Ian. Ian had been the victim of 'fag' bashing last Saturday night as he walked to a 7-11 store for cigarettes. As a result, he had a broken nose, internal injuries, and a broken arm. Next week they will x-ray his arm again and see if a pin has to be inserted surgically. I can't imagine the horror he went through, nor will I even understand the mind of the people who would do such an act. I can't imagine what satisfaction there would be or what motivation for such an act could be. I was beaten up several years ago when I first moved from Toronto. . . . It was horrifying to be a victim of such ignorant, generic hatred. What could be the cause of such deep-rooted hatred? These people (and I use the word loosely) must have ugly lives - lives void of caring and love.*
>
> *The really frightening aspect of this prejudice and hatred is that it is on the upswing world wide. . . . What and who motivate the ignorant to promote their own agendas?*
>
> *When I was a consultant, I was a member of SPEDS (Society for the Prevention and Elimination of Discrimination and Stereotyping). We*

> *authored materials which were available throughout the province of Alberta. I often wondered if these materials made a difference? . . . . It's obvious the police weren't going to do very much. If the person were straight I'm sure there would be more detailed investigation of the crime. It was something else we had to put up with as gays. (Wayne, April 10, 1992)*

Wayne's perception of lack of social support (i.e., the police) indicates the degree to which the homosexual person is forced into a devalued, and vulnerable existence. The threat of violence intensifies when there is a potential lack of justice.

I have been the target of homophobic comments. I ponder the intentionality and calculated cruelty of such remarks as, "I don't want my children around anyone gay or anyone HIV positive." I sadly wonder, do they reflect a lack of knowledge, a fear, or is it a maneuver of power and control?

When confronted with homosexuality and/or HIV/AIDS in their midst, families can either challenge their predominantly heterosexual values and re-examine some of their assumptions about homosexuality or they can become even more deeply committed to maintaining the status quo. For many individuals, families, groups, and communities, they accept and embrace as a gift for personal human enrichment, the opportunity presented by an infected family member to expand their consciousness.

Internalized Homophobia

Walter's description of a friend's funeral illustrates that homophobia is not only present in mainstream society but is evident within the gay network.

> *It's really strange, there were a lot of people that were close to this person that would not go to the funeral service because they thought, "Well, if we're seen there then we're automatically going to be picked out as being gay." And I thought, "How rude. How disrespectful."*
>
> *They had all gone on trips together, but they would not go to the funeral. They wouldn't even send a card or flowers or anything. (Walter, 1993)*

The funeral of a gay person often demonstrates the clear division between secret versus public life of the deceased. The people attending the funeral often migrate into a seating arrangement similar to that at a traditional wedding. Instead of the bride's family on one side and the groom's on the other the division is the biological family verses the selected nurturing family. On many occasions the mask of deception continues throughout the service: there is no acknowledgement of the person's real life, how they have loved, their identity or the fact that the death was AIDS related. Rather than celebrating the uniqueness of the person's life, the eulogy gives a generic account that could represent anyone's life. The funeral becomes another reinforcement of the devaluation and depersonalization of the authentic person and the mask of duality is carried on about the individual even into death.

Multiple Gifts

'Life is Not a Dress Rehearsal'

Losses and gifts are both part of the dynamic paradox of living with HIV and I struggle to find the most accurate words to describe this contradiction. Individuals with HIV are moving in two directions at once. Premature death is still the ultimate outcome for infected persons, yet most of their energy is directed toward being fully alive. They share the bleakness of deep depression at the same time as they reflect on the new spiritual richness and inner strength made possible by the disease. They talk of the oppression in silence, and of the power they reclaim by engaging in political action and community education to make the future better for others. They struggle with their lack of faith and confidence in traditional health care, and yet they compensate for weakness in the existing system by reclaiming and taking ownership of their bodies and wellness.

When faced with the certainty of mortality, life suddenly becomes a precious limited resource. There is a re-evaluation of how and with whom time is spent, the quality of life is cherished as quantity dwindles. *"You start to prioritize things, and mentally start listening to what is important. You go into yourself, look for energy, try and keep things in perspective, try and account for everything that goes on in your life." (Walter, 1993)*

"*Life is not a dress rehearsal,*" is the motto Wayne has lived by for years. Even with the disease, he continues to travel as this has always been a priority for him. Traveling becomes more difficult as time goes on, and involves some risk taking. It is illegal for a HIV positive person to enter the United States (U.S.), and so to travel to the U.S. becomes difficult. AIDS patients are faced with questions such as: Do I stop taking my anti-virals so customs do not question the pills? Do I risk getting sick on the holiday knowing my health care wouldn't cover me?

Life and time are gifts, and with those gifts comes a sense of impatience and frustration when time and resources are wasted and destructive relationships endure. Those near death feel an urgency to preach to others about the value of life. *"Everyone should be told they have HIV and their days could be numbered - it makes you separate the wheat from the chaff in a big hurry," (Anonymous personal conversation with HIV/AIDS infected person, 1993).*

Gift of Inner Strength

With the label of HIV positive comes the panic and fear of an altered sense of the future. Change becomes a constant state, and making sense of the changes is continuous. Life as you know it is altered: *"It is a very uncomfortable feeling because you're questioning yourself, you question your own values, your worth, your sense of being, " (Brian, 1993).* "Living with HIV/AIDS is like a roller coaster ride or living in a twilight zone, as there are constant changes happening internally and externally. I experience the spiritual, emotional, physical, intellectual and social changes; no aspect of my being remains familiar and comfortable." (Dr. Peter, 1992, Vancouver)

> *The concept of change is a regular topic among HIV/AIDS patients. Dealing with constant change is a very difficult thing to do. Coping in a world that refuses to be routine is very taxing. Just when you believe everything is on track, something else changes - your medication, your* CD_4 *count, your employment. . . disease eventually leads to changes in all areas, work and recreation, and event that comes. Change in self-worth and self-esteem.*

> *There is a constant readjustment to the demands and expectations placed on you by the illness. In my work life and social life I used to relish the idea of constant and regular change. Now I relish the idea and concept of regularity - there is a loss of comfort and routine - change is a never ending challenge - it comes so quickly you never become comfortable. (Wayne, November 16, 1992)*

At the same time he is dealing with external changes (employment, health care relationships), he is also having to re-acquaint and renegotiate new ways of being with his own body. The people I talked with all discussed the deep sense of spiritual crisis as they reflected on questions such as: "What is the meaning of life?" "How do I fit with the world?" "Why me and what is left to value about myself?" Depression is an opportunistic companion, that comes with these soul searching questions, as each infected person tries to reframe his life story with the pressure of time and limited energy.

Depression was a universal companion as people experienced spiritual crisis, but the depression manifested itself differently for different individuals.

> *The rail of depression slowly lowers its shadow and gradually shades your [my] perspective. I've discovered that I've stopped listening to CBC, so my days are spent alone and in silence. The signs continued to progress. Sometimes I have the inner feeling of fear that seems to be constantly gnawing away at you. The fear is undefined - a fear that gradually corrodes your strength and soul. . . . It's a fear that makes your palms wet, wrinkles your brow and accelerates your heart in. . . time is marching on. . . . It's the fear I felt when I saw Dr. Peter in Vancouver or when I watched Yale hobble with*

> *his cane and strain to lift his leg over the balcony door.... I wonder if others fear losing me with that same sense or urgency and panic... with fear I don't feel anger - just frustration. (Wayne, November 23, 1992)*

And it progressed.

> *I've been lonely but haven't wanted to talk to anyone. (Wayne, December 14, 1992)*

The fear remained and the depression continued to engulf Wayne. Wayne's depression had a slow way of segregating him from the rest of the world. In the early diary entries he grieved the loss of the rhythm of life as it revolved around the events and interactions of the school year. These comments were general and he did not label them as depression. In April, Wayne began to name the experience.

> *I've been very depressed since early December. Winter, cold, darkness, combined with Christmas season... Its the deepest depression I have felt to date. It was as though a huge weight had been placed on my shoulders and everything seemed foggy. Although I am aware of my symptoms, I was powerless to do anything about it. Pollyanna remarks of 'get up and get going' were very unwelcome. (Wayne, January 14, 1993)*

During this period Wayne had decreased contact with almost everyone. He stopped writing. He was trapped. As his sister, it was difficult to watch as he folded and collapsed inward. I had no sense of how to help.

I felt useless as I was unable to permeate the cocoon that insulated Wayne from the rest of the world. As a sister and a nurse, I wanted to fix the problem. I was scared. There were times when Wayne's expression was so flat and despondent that I worried about suicide. He was withdrawing and I found myself forcing conversations with him. I was impatient and insensitive to his experience at that time. It was only later when I was swallowed and lost in the bleak paralysis of my own depression that I began to see the meaning of the depression experience.

> *Life seemed to be on the other side of a very thick pile of glass for me. I feel particularly paralyzed in depression - I knew what was going on, but I was incapable of acting on anything. It was the first time I've thought seriously about suicide, and the first time I thought I needed major drug intervention or hospitalization. (Wayne, February 15, 1993)*

Wayne resurfaced from this depression with a renewed sense of hope. He became angry and publicly outspoken. The internalized anger had facilitated his depression; now he was directing his anger outward. He raged about the lack of rights for homosexuals, joined the Liberal party and helped to campaign for the Liberal candidate in his riding. He joined a gay and lesbian organization and became active in planning strategies to lobby the government on issues critical to homosexuals.

> *One week ago today, I attended a public rally at McDougall Center to support a strong independent Human Rights Commission in the province of Alberta, and to support Human Rights legislation including sexual orientation. It was one of the most public things I have ever done. It felt wonderful. I can feel the gradual awakening of a political spirit trapped within, and a very deep desire to feel some liberation as a gay man in this province. This is also the third week I have done some office volunteer work for the gay organization. Although what I 'm doing sounds minimal - at least now I am part of a solution. (Wayne, February 15, 1993)*

Wayne kept reacting to unjust remarks. One evening which watching the five o'clock news, the reporter spoke of a tennis star who had died from AIDS. The reporter concluded by saying, "This death is tragic as this person is one of the innocent victims of AIDS." Wayne immediately phoned the station and demanded they air an apology to all persons who they would consider were not innocent victims. He wrote letters to the president of the station and the reporter. He did receive a letter of apology, but most importantly he was no longer silenced and he was actively resisting his oppression as a gay man infected with AIDS.

Wayne's public, political action was complemented with a new sense of spirituality. He began to see spiritual connections in all things, and had a renewed sense of interdependency and interaction. There was a new expression that physical death did not equal spiritual death. Wayne and I had talked about the spirit of my Grandma Bray, who frequently visits both of us, and the restless spirit of Russ, Wayne's former lover, whom he feels occasionally present.

> *Death comes to us in many ways.*
> *It is in a broken flower,*
> *in a carrot we eat*
> *or in a small child.*
>
> *Death is ugly and beautiful.*
> *It is useful and wasting.*
> *It is tragic and happy.*
> *It is in everything and*
> *It is everything.*
>
> (Chief Dan George,1982, p. 1)

This poem by Chief Dan George captures that feeling of connection and the cycle of life, and the contrast with death.

Wayne's depression also illustrates contrasting purpose. At first his depression isolated and alienated him from the world, and rendered him flat and despondent. Then he emerged from the depths of depression with a renewed integration of mind and spirit, keen to reunite with the world in a different way.

Brian is still plagued with bouts of depression.

> *It's the fear of the unknown, what and when is it (death) going to happen? There's always a clock going on - tick, tick, tick, tick, tick. . . It's helplessness, loneliness . . . I feel drained. . . don't feel like eating, or getting out of bed. . . or communicating. It's implosive. I want everything to stop, just to be done. (Brian, 1993)*

For short term re-energizing, Brian retreats to bed for a day or two. For his long-term strength, he depends on his belief in a higher being. *"I'm a non-practicing Catholic. I believe in a higher being, but I don't believe in the church right now."* The presence of a Higher Being gives him hope that prayer might bring the possibility of a miracle. He also feels a sense of protection, and feels this Being gives him the inner strength to be an individual. To live, to experience and to learn. The spirit guides but Brian feels free to make choices. *"I believe in reincarnation as another person or being or thing to better the next life or I could be learning from a previous life."* Brian sees death as a natural part of life as he elaborated.

> *It's like a chronic disease, if you want it to eat you up it will. I think the only thing that would be sorrow is the actual*

> *leaving the earth, but we are all going to have that experience. It's not unique to me that I'm going to die. (Brian, November, 1993).*

He does not see anything unique about dying from AIDS, as he feels that all deaths are reduced to some meaningless statistic which is of no consequence to the dead. He talks about his family and their connected inner strength that keeps him re-energized in life.

Walter talks about his Catholic roots, and how he attended church every Sunday for years, but gradually he no longer felt a part of that religious community. He now attends mass on rare occasions, but his main source of spiritual strength is the rituals and prayers he has established on his own. He said he often prays while gardening and doing yard work and he feels the spiritual connection in this work.

This constant deep resource of inner strength is often the only stable force amidst the dynamic changes of with HIV.

The Gift of Body Listening

The medical label of HIV positive creates a panic reaction in the infected person that lasts for the first few months. Brian and Walter were convinced they would die immediately. Walter had felt sick for a long time and had visited the doctor several times and had a variety of tests done. When the regular tests did not identify the cause of his illness, he finally suggested to the doctor that an HIV test be done. Walter's doctor was shocked when the HIV results were positive.

> *When he got the test results back he was just horrified. He said, "I can't believe this. I don't believe it. Your don't look like you are but you have all the symptoms." I was tired, I wasn't sleeping, I was so run down. He said, "I'm going to run it [HIV test] again." So, for a week and a half we waited and it didn't bother me really a whole lot. I told some of my friends that I tested positive, but the doctor is retesting. My friends said I almost seemed happy, and I said, "At least I know what was causing the problem." (Walter, 1992, p. 12)*

Prior to the test, Walter's doctor was not aware of his sexual orientation, and Walter was his first HIV positive patient. Walter's words are a classic example of the power of a medical label to legitimize symptoms the person experiences. The medical label gave him and the doctor a starting point for discussion. At the time of diagnosis, Walter and Brian had tremendous faith that the doctors could help and would have an understanding of what was happening.

Wayne's awareness of HIV as a chronic non-curable disease has increased. But even with this awareness, He still experiences the pre-visit anxiety and has the expectation that maybe this time he will leave the doctor's office with some answers about his condition. The longer he has the disease the more he realizes that medical intervention, like the physical indicator of the disease, is only one small part of a huge puzzle. Working on the puzzle is a process for both the patient and doctor of trial and error, trying to figure out how the pieces fit together.

> *The clinic physician always says not to put too much weight on the T4 count, but then turn around and change medication, react with anxiety or relief etc.*

> *depending on the count. The count dictates policy about full blown AIDS, long-term disability, onset of anti-viral drug treatment. . . . How can they say not to put much emphasis on the results. Every time you wait for the results it's like the first time. Nervous anxiety builds and you wait dry mouth, palms sweaty and tense. . . . Perhaps when you are really ill the T_4 is less important. (Wayne, March 23, 1992)*

Over time the doctor's role shifts and the medical labels doctors bestow on AIDS patients have less impact. Health care professionals become more of a partnership arrangement and the individual becomes increasingly aware of the importance of self-care and listening carefully to his/her own body cues. The body is an unpredictable partner for a person with AIDS at the same time as being his most intimate companion. He has to readjust his consciousness and become flexible enough to listen to his body for clues of how to pace his activities and to continue living. Body listening gives him valuable self-care information.

> *As I live with this disease I'm learning how important it is to pace myself with all activities. . . . It's frustrating not always being able to jump in the pool and go like hell. . . . It's a matter of listening to your body. . . . HIV had made me more aware of myself and my physical and psychological characteristics. (Wayne, September 1, 1992)*
>
> *One thing I learned this trip is three weeks away is maximum. I was exhausted when I got home. (Wayne, September 2, 1992)*
>
> *My attitude toward the clinic and my doctors has changed. They don't have all the answers as I once hoped they would. I'm more in touch with my own physical, emotional and spiritual body than ever before. It talks to me about what is and what is not okay - it tells me when to sleep and when*

> *to go like hell. My spiritual body tells me about positive thought, love and healing. It's because of this 'body talk' and my sense of internal empowerment that I feel a true partnership with my doctor to 'care' for me and treat my condition. Because of these feelings I don't fret or have the huge feelings of anxiety I once held about the clinic results. Lab results and T_4 tests no longer dictate how I feel or how I 'should' be feeling. (Wayne, September 21, 1993).*

Wayne talks at great length about the importance for him of all his basic self-care activities. To him, the most important of these is activities to sustain a positive attitude. To sustain his positive attitude takes work and commitment. When he looks at the depressive times in his life he realizes how negative his thought patterns were. Now he has the insight to recognize how destructive these negative thoughts can be, decreasing his feeling of well-being. When Wayne swims he repeats positive affirmations and visualization of living in a strong healthy body.

Humor and laughter also seem to be vital components of self-care.

> *It's amazing how open, perhaps flippant, our conversations about HIV might appear to someone listening to a recording. Curtis said he would be known as the first person to have salmonella pneumonia and salmonella in his blood at the clinic. (Wayne, April 10, 1992).*

Wayne describes how his group of friends roared with laughter as Curtis told his story about having systemic salmonella. The clinic staff were in a panic because they were not sure of the appropriate chemotherapy and treatment for salmonella pneumonia and septicemia. Curtis trusted his own judgement and realized he did not feel any worse than he had felt for the past few weeks; so carried on with his original plans to meet his friends for lunch. The friends thought it was humorous to contrast the reaction to this diagnosis between the doctors and nurses compared to Curtis. To the health care professional the diagnosis of systemic salmonella was of great concern; to Curtis, it was just one more medical label to take in his stride as he continues living to his fullest potential at this point in time. The medical labels and physical indicators of illness become less and less significant as the person with HIV is constantly adapting and renegotiating new ways of being present in a changing body.

As the disease progresses the changes happen faster and faster and it is difficult to keep tuned and make sense of the changing body. Two weeks before his death, Dr. Peter spoke at the Vancouver conference about the fact his body was changing so rapidly that he no longer had a chance to adjust or cope with the changes. Yale, a friend of Wayne's and mine, talked to me three weeks before his death and stressed that everyday now he is challenged by major changes in all areas of his life. He said, "The changes are so fast and so many that I cannot keep up." For Dr. Peter and Yale, their bodies became unpredictable, uncomfortable companions and listening to the "body talk" was overwhelming. They felt like visiting strangers in their own bodies as death advanced from the wings.

> *I wonder if death comes when you stop trying to cope with the challenges or the constant deterioration of your body just exhausts your mind and your soul. Sometimes I have an inner feeling of fear. Fear that*

seems to be constantly gnawing away at me. The fear is undefined, a fear that gradually corrodes my strength and soul. It is the fear of the unknown and perhaps fear of the future. It's a pleasant thought to be able to stop time and lock myself in the present, a pleasant but very unrealistic thought. I feel this fear anytime, when I lie in bed at night, when I go for walks, or even when I'm with friends. It's a fear that makes your palms wet, wrinkles your brow, and accelerates your heart beat. It's a reminder that time is marching on and your time has new limitations imposed on it. It was the feeling of fear I felt when I saw Dr. Peter at the AIDS conference in Vancouver, and when I used to watch Yale hobble with his cane and strain to lift his leg over the balcony door railing. I wonder if other people fear losing me, and have a similar sense of urgency and panic? (Wayne, November 16, 1992).

Epilogue:

Walter:

At a point where the virus has facilitated every personal loss possible, the individual finds a renewed sense of personhood and claims the strength and courage to open a window to make their personal experience public. So at the time the virus is circling in and limiting the individual, the individual is circling out and has a new sense of power through collective public social action.

Walter described this need as a "calling." Earlier in his life, he had been asked to consider being a Catholic priest. While that choice never felt right for him, he nows feels the commitment of a "calling" to make his story of living with HIV/AIDS public. He gave little consideration to the social ramifications of going public. He felt the only important issue was to have people become more aware by talking about preventing the spread of HIV. He wanted to talk with young people and motivate them to make conscious, responsible decisions about their sexuality and sexual practices. He became involved with a high-school peer support student group in a local small town. he worked with these students to produce a play. This dramatic education program was presented to parents and peers. The peer support teams of other schools are now interested in becoming involved and producing a similar type of community education program. This proved to be a positive experience as the students had an opportunity to dismiss labels and work on a personal level toward a common good.

Walter participated in the Canadian AIDS Society annual meeting in Ontario as a way of having the voice of HIV positive people heard. Once Walter was on leave from work he no longer had to maintain the duality of living with the secret of his sexual orientation and HIV status. His private voice became his public voice and he could honor his calling to educate others.

Wayne

Sunday, February 27, 1994

I have just arrived at Wayne's apartment in Calgary on my way home from a nursing conference in Saskatoon. As always, I am glad to see Wayne, but even more so this visit. He has been sick lately and is low in energy. He is still recovering from an infection in January that the doctors were never able to diagnose.

In January, Wayne had gone to visit a friend, Earl, in Vancouver. The day after his arrival at Earl's Wayne became sick. All his glands were swollen; he had a fever and a raw swollen throat with open sores on his soft palette the size of a dime. Physically, he felt terrible but the major insult was the emotional and spiritual impact of this latest illness. The symptoms forced him to return home after 48 hours in Vancouver. The disease was, and continues to dictate and control all aspects of Wayne's life.

At this time, Wayne saw several AIDS specialists. They were all stumped as to the cause of the open sores. All the blood tests and swabs had not isolated the pathogen. The doctors prescribed steroids to promote the healing of the sores. Wayne started on another trial drug as prophylactic treatment for CMV. The sores healed but his energy level continued to be low, and he had to pace even more carefully his activities of daily living.

Two months later, Wayne still talks about the flight home from Vancouver in January. *'You know, Joan, I felt so sick all I could think about on the plane was will I make it home and how desperately I longed to be in the comfort of my own home.'*

Wayne's home has become a haven of comfort. From the moment I open his door, I can feel and see his presence everywhere. He loves his home and takes great pride in creating and maintaining a sense of comfort and warmth. The uniqueness, quality and richness and depth of his character is projected into every corner of his home. The hardwood floors are accented by various carpets and rugs; each with its own story of where and why it was selected or given to Wayne. The walls are painted daffodil yellow with contrasting deep grey to compliment his much loved, and diverse, pieces of art. Even the colors of the walls have a wonderful story of friendship brushed in the paint.

Every year Wayne has a reunion visit with two of his friends, Earl and Brenda. Earl lives in Vancouver, Brenda in Toronto, and both are interior designers. Three years ago the visit happened in Calgary, consequently they all had input into selecting the new bold colors for Wayne's walls, a process that involved great discussion and fun.

Every painting and piece of art work has its own story. Robbie, a woman Wayne loves dearly and team taught with for several years, is also an artist and her picture of irises graces his bathroom. Roger Wood, an artist friend from Toronto, has given Wayne several pieces of "Box Art." Yale's father from Winnipeg is a sociology professor and artist. One of his water colors has a central place in

Wayne's living room. Several paintings, all unique and different, Wayne purchased on his various world travels.

There are no neutral, generic spaces in Wayne's home. The place is a celebration of his life; there is story, history, and meaning everywhere.

As Wayne and I sit in the bright sunshine in his dining room looking out the corner window at the river and Lyndsay Park, our conversation has an agenda. I need to, and want to, talk to Wayne about this paper, my final one-credit project for my Master's degree in Education. I am nervous as I share my writing with him and discuss the themes of the paper. My written words seem limited compared with the richness of the experience, not just the experience of living with HIV but the experience of our lives together and apart As he reads, I struggle not to interject. Finally I ask, "So, what do you think?"

> *It's good. It's truthful, but you have missed an important part. I do not want people to read this and see a tragedy. I want people to know how blessed my life has been. Joan, I truly believe 'Life is not a dress rehearsal.' Sometimes I even think that life is not divided up in years, but maybe life is given out with a certain number of events as a quota. Maybe my life has been so blessed I used the quota up early.*
>
> *Somehow you have to get the reader to understand all the blessings in my life. I have: had the opportunity for education, first in optometry then education; worked in a career I loved and felt valued and good at; warm, loving friends, my friends are such a gift, I have close gay and straight friends and I count that as a unique privilege; travelled to many, many*

countries; and John as a friend and partner. These are the rich blessings of my life. People need to understand how lucky I have been.

Following this conversation, Wayne suggested we go for a walk. We both love to walk and have taken the path along the river to Stanley Park a million times. Today the walk and the talk was different. My agenda of the paper over, Wayne declared he had an agenda of his own that he wanted to discuss. As we walked we planned the celebration of his memorial service: the eulogy, the greeting of friends, the music,and the reception. Wayne is incredibly brave and proud. I listened as he spoke, and struggled to concentrate as the tears streamed from my cheeks onto my coat. He assured me that he is not afraid of being dead, but after this last illness he is afraid of the process of dying.

April 20, 1994

Wayne is currently in the Holy Cross Hospital. The doctors still have not been able to diagnose the source of infection. Wayne has incredible bone and neurological pain; deep, hot, sharp pain that leaves him immobilized. On March 1, he had swelling and pain in all his upper body muscles and connective tissue and was sensitive even to light touch. The pain then progressed and localized in the bones of his ribs and sternum. The amount of suffering he endured before entering the hospital on March 30 was brutal. He was in hospital for seven days before they changed his analgesic and started him on Dilaudid, a major narcotic, thus achieving some relief and control over the pain.

Wayne has had multiple investigative tests: blood cultures, urine cultures, sternal bone marrow, lumbar puncture, bone scan, Gallium-67 body scan, magnetic resonance imaging (MRI), stool cultures; but still no diagnosis. His body temperatures have ricochetted from 35-42°C bringing on horrendous night sweats, nausea and vomiting.

Now Wayne is struggling to make peace with a body that is an unpredictable, uncomfortable, companion. I spent this past weekend with Wayne in his apartment. He feels very stoned on the Dilaudid and said, "*I do not have the sharp pain anymore, but then again I also don't have much of a sensation of 'body' anymore either.*" The cruel reality is that every now and then a breakthrough of sharp pain, has an instant way of grabbing Wayne's attention and making him acutely aware of, and totally focused on, his body. The pain represents the physical reality of HIV/AIDS as an uncomfortable companion.

At this moment, preoccupied and consumed by the haunting image of Wayne's pain, I have lapsed into silence as I struggle to regain the vision of Wayne's blessed life.

References

Frankl, V. (1959). Man's search for meaning: And introduction to Logotherapy. Toronto: Touchstone Books.

George, Chief D. (1982). My spirit soars. Surrey: Hancock House Publishing.

Kubler-Ross, E. (1969). On death and dying. New York: MacMillan Publishing.

Kubler-Ross, E. (1987). AIDS: The Ultimate Challenge. New York: MacMillan Publishing.

McGough, K. (1990). Assessing social support of people with AIDS. Oncology Nursing Forum, 17(1), 31-35.

Nokes, K. M., & Carver, K. (1991). The meaning of living with AIDS: A study using Parse's theory of man-living health. Nursing Science Quarterly, 4(4), 175-179.

Sewell, R., Bramlett, M., Gueldner, S., Gritzmacher, D., & Martin, G. (1991). The lived experience of survival and bereavement following the death of a lover from AIDS. Image: Journal of Nursing Scholarship, 23(2), 89-94.

Shilts, R. (1987). And the band played on: Politics, people and the AIDS epidemic. New York: St. Martin's Press.

vanManen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. London: The Althouse Press.

Young, I. (1990). Five faces of oppression. Justice and the politics of difference (pp. 39-65). Princeton: Princeton University Press.

Bibliography

Bellert, J. (1989). Humor A therapeutic approach to oncology nursing. Cancer Nursing, 12(2), 65-70.

Callen, M. (1991). Surviving AIDS. New York: Harper Collins Publishers.

Canadian Nurses Association. (1992). HIV/AIDS Education for nurses. Ottawa: Canadian Nurses Association Publication.

Carmack, B. (1992). Balancing engagement/detachment in AIDS-related multiple losses. Image: Journal of Nursing Scholarship, 24(1), 9-14.

Corr, C. (1993). coping with dying: Lessons that we should not learn from the work of Elisabeth Kubler-Ross. Death Studies, 17, 69-83.

Cox, E. (1990). Thanksgiving: An AIDS Journal. Toronto: Harper & Row Publishers.

Ferrell, J., & Boyle, J. (1992). Bereavement experiences: Caring for a partner with AIDS. Journal of Community Health Nursing, 9(3), 127-135.

Gray, R., & Doan, B. (1990). Empowerment and persons with cancer: Politics in cancer medicine. Journal of Palliative Care, 6(2), 33-45.

Halfe, L. (1989). The circle: Death and dying from a nature perspective. Journal of Palliative care, 5(1), 37-41.

Hall, B. (1990). The struggle of the diagnosed terminally ill person to maintain hope. Nursing Science Quarterly, 3(4), 177-184.

Hein, K., & Digeronimo, T. (1989). AIDS: Trading fears for facts. New York: Consumers Union.

Hildebrand, J. (1989). Working with a bereaved family: Focusing on prevention not pathology. Palliative Medicine, 3(2), 105-111.

Hunt, M. (1991). Being friendly and informal: Reflected in nurses', terminally ill patients', and relatives' conversations at home. *Journal of Advanced Nursing*, *16*, 929-938.

Jenkins, H. (1989). The family and loss: A systems framework. *Palliative Medicine*, *3*(2), 97-104.

Jordan, M. (1989). *Losing Uncle Tim*. Niles: Albert Whitman & Company.

Kelly, J. (1992). Grief: Reforming life's story. *Journal of Palliative Care*, *8*(2), 33-35.

Kelly, P. (1992). Counselling patients with HIV. *RN*, *2*, 54-58.

Kubler-Ross, E. (1975). *Death: The final stage of growth*. New York: Touchstone Books.

Larson, E., & Ropka, M. (1991). An update of nursing research and HIV infection. *Image: Journal of Nursing Scholarship*, *23*(1), 4-120.

Lego, S. (1994). *Fear and AIDS*. Albany: Delmar Publishers.

Levine, S. (1982). *Who dies? An investigation of conscious living and conscious dying*. Toronto: Doubleday.

Mersenhelder, J., & LaCharite, C. (1989). Fear of contagion: A stress response to acquired immune deficiency syndrome. *Advances in Nursing Science*, *11*(2), 29-38.

Moffat, B. (1986). *When someone you love has AIDS*. Scarborough: NAL Penguin.

Monette, P. (1988). *Borrowed time: An AIDS memoir*. New York: Harcourt Brace Jovanovich Publishers.

Nerken, I. (1993). Grief and the reflective self: Toward a clearer model of loss resolution and growth. *Death Studies*, *17*, 1-26.

O'Berle, K., & Davies, B. (1992). Support and caring: Exploring the concept. *Oncology Nursing Forum*, *9*(5), 763-767.

O'Conner, N. (1989). Letting go with love. Toronto: Bantam Books.

Overall, C., & Zion, W. (1991). Perspective on AIDS Ethical and social issues. Toronto: Oxford University Press.

Pallotta-Chiarolli, M. (1991). Someone you know: A friends farewell. Kentown: Wakefield Press.

Peabody, B. (1986). The screaming room. San Diego: Avon.

Preston, J. (1988). Personal dispatches: Writers confront AIDS. New York: St. Martin's Press.

Reimer, J., & Davies, B. (1991). Palliative care: The nurse role in helping families through the transition of "fading away." Cancer Nursing, 14(6), 321-327.

Richardson, A., & Bolle, D. (1992). Wise before their time. London: Harper Collins Publishers.

Rolland, J. (1990). Anticipatory loss: A family systems developmental framework. Family Process, 29(3), 229-243.

Sandelowski, M. (1991). Telling stories: Narrative approaches to qualitative research. Image: Journal of Nursing Scholarship, 23(3), 161-166.

Saynor, J. (1988). Eristentialism and spiritual concerns of people with AIDS. Journal of Palliative Care, 4(4), 61-65.

Shaw, M., & Halliday, P. (1992). The family, crisis and chronic illness: An evolutionary model. Journal of Advanced Nursing, 17, 537-543.

Siminoff, L., Erlen, J., & Lidz, C. (1991). Stigma, AIDS and quality of nursing care: State of the science. Journal of Advanced Nursing, 16, 262-269.

Smith, G. (1990). Recognizing personhood and the right to die with dignity. Journal of Palliative Care, 6(2), 24-32.

Smith, L., & Lathrop, L. (1992). AIDS and human sexuality. Canadian Journal of Public Health, 84(1), S14-S18.

Smith, N. (1990). the impact of terminal illness on the family. Palliative Medicine, 4, 127-135.

Smith, N. (1993). Managing family problems in advanced disease - A flow diagram. Palliative Medicine, 7, 47-58.

Sontag, S. (1989). Illness as a metaphor: AIDS and its metaphor. Toronto: Doubleday.

Stewart-Giacquinta, B. (1989). Researching the effects of AIDS On families. The American Journal of Hospice Care, 6(3), 31-36.

Thorne, S., & Robinson, C. (1989). Guarded alliance: Health care relationships and chronic illness. Image: Journal of Nursing Scholarship, 21(3), 153-157.

Underwood, S. (1990). Touchstone: Finding a lump in the breast. Phenomenology & Pedagogy, 8, 189-208.

Wallerstein, N. (1992). Powerlessness, empowerment, and health: Implications for health promotion programs. American Journal of Health Promotion, 6(3), 197-205.

Wright, F. (1991). The role of the family as a support system for people with AIDS. Nurse Practitioner Forum, 2(2), 134-136.