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POSITIVE LIVING

A MANUAL FOR PEOPLE
AFFECTED BY AIDS/HIV

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AFFECTED BY AIDS/HIV**

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With AIDS Society**

**1st Edition
June, 1993**

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DEDICATION

POSITIVE LIVING: A MANUAL FOR PEOPLE AFFECTED BY AIDS/HIV is a resource guide intended as a first step information source on the issues involved in living with AIDS and HIV.

The Manual has been produced by the Vancouver Persons With AIDS Society with contributions from members and staff, and in consultation with other AIDS community groups in British Columbia.

The material contained in this Manual is based on the experience of many people living with AIDS and HIV.

The editorial team of the Manual would like to acknowledge the inspiration and example set by Frontliners in London, England and the New York PWA Coalition, whose publications on living with AIDS provided us with guidance and direction.

We would also like to acknowledge the strength and contributions of the many members of the PWA Society whose dedication made this publication a reality.

In particular, this Manual is dedicated to
Kevin Brown, Warren Jensen, Taavi Nurmela,
Steven Scribaillo and Alex Kowalski.

ACKNOWLEDGEMENTS

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Vancouver Persons With AIDS Society Treatments Information Project Disclaimer

In accordance with its mandate to provide support activities and facilities for members for the purpose of self help and self care, the Vancouver PWA Society operates a Treatment Information Project to make available to members up to date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV related conditions. The intent of this Project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatments Information Project provides all research and information to members without judgement or prejudice. The Project does not recommend, advocate or endorse the use of any particular treatment or therapy provided as information. The Board, staff and volunteers of the Society do not accept the risk of, nor responsibility for, any damages, costs or consequences of any kind which may arise or result from the use of information disseminated through this Project. Persons using the information provided through this Project, including the information found in **Positive Living: A Manual for People Affected by AIDS/HIV**, do so by their own decision and hold the Society's Board, staff and volunteers harmless.

INTRODUCTION

**Welcome, reader, to this first edition of POSITIVE LIVING:
A MANUAL FOR PEOPLE AFFECTED BY HIV/AIDS.**

This resource guide is intended to arm you with information to make life with HIV/AIDS less fearful and frustrating. We have attempted to deal with many of the things you'll need to know from the issues involved in simply being tested, to emotional and medical problems you may encounter, practical considerations like work and housing, and the spiritual side of living with HIV/AIDS. We believe this knowledge can give you more control over your own life, help you better care for yourself and your loved ones, and help you work with health care providers to obtain the best care possible.

We endeavour to provide answers to these concerns within this manual, rather than just direct you to someone else. But others can help. The caregivers in our province will welcome contact with you. Draw upon their experience and expertise for your support needs. In exchange, you'll meet the sensitive and understanding people who are there to help you face this challenge. Your peers are also here to help and understand as you come to terms with these new demands. We are all living with HIV/AIDS; either as someone infected by HIV/AIDS or affected by HIV/AIDS.

You will find that your needs for support and information will tend to vary and we hope you will refer back to this guide from time to time as these needs change. We also want to hear your comments and criticisms of this guide so that future editions will be better.

Learning that you have HIV/AIDS is a shock. It is not an automatic death sentence, however at times it may feel as though your entire world has been blown apart. Fears, uncertainty about your future, rejection and discrimination are to name but a few of the thoughts you may be wrestling with. But you are not alone. Take help when you need it and give help to others when you feel strong. Together, with one another's support we can live positive, productive lives for a long, long time.

CHAPTER ONE: COMING TO TERMS WITH THE DIAGNOSIS

A. TESTING FOR HIV STATUS

What is HIV?

It is widely believed that AIDS is caused by a virus called HIV (Human Immunodeficiency Virus) which attacks and destroys the immune system. This leaves the body vulnerable to all kinds of illnesses including rare types of skin cancer, pneumonia, TB, meningitis and cognitive impairment (dementia). There is still debate over how HIV actually causes AIDS. There is, at present, no cure for HIV infection.

It is not known whether co-factors such as alcohol or drug abuse, poor nutrition, stress or other illnesses play a role in immune suppression; how long it takes for the initial infection to develop into AIDS (although it has been proven to take up to ten years); or whether infection with HIV makes it absolutely certain that a person will ultimately develop AIDS. It is known how HIV is and is not spread and how to protect against infection with the virus.

Any human being is a potential target for HIV: man, woman or child. However, there are only a few very specific ways the virus can be passed from one person to another and all avenues of infection involve the direct exchange of bodily fluids between people. The virus is very fragile and can only live for a few seconds once exposed to the air. This means that it cannot be passed through casual contact such as sneezing and coughing, or sharing dishes and utensils. It cannot be passed by insects nor through food or water. It cannot be passed by kissing, and hugging is completely safe.

HIV is carried in the blood and bodily fluids of infected persons and can be passed to another individual:

- . By penetrative anal and vaginal intercourse without a condom;
- . Through the sharing of hypodermic needles used for injecting drugs or vaccines;
- . Through transfusion of infected blood or blood products;
- . From an infected mother to her infant before or during childbirth, or through breast milk;
- . Through transplanted organs or donated semen; and
- . Through the use of contaminated instruments in such practices as tattooing, ritual scarring, and circumcision.

What Does the Test Mean?

Current HIV tests cannot detect the virus itself. The two tests used, the ELISA and Western blot tests, both search for antibodies to HIV which show that, at some time, the virus has been present in your body. Researchers believe that the virus, once present, remains. However, people infected with HIV do not produce detectable antibodies for an average of six weeks (some

for as long as six months). There seem to be certain individuals who never produce antibodies, even though the virus may be present.

Neither HIV test is foolproof and both rely partly on the interpretation of results by the testers. ELISA is used most often as a screening tool, followed by the Western blot for verification. Used together by experienced diagnosticians, they can be highly, if not completely, accurate. Although such cases are rare, both tests have been known to produce "false-negative" results, indicating the virus is not present when in fact it is, and "false-positive" results, indicating the virus is present when, in fact, it's not. The use of both tests together tends to guard against inaccurate readings.

There are good reasons to consider being tested for HIV. Many treatments are now in place which relieve the symptoms of HIV infection. Diseases such as pneumocystis pneumonia (PCP), a rare form of pneumonia associated with HIV immune suppression, are treatable and preventable. There is also much work being done on therapies which enhance the strength and function of the immune system. Knowing your HIV status will allow you to treat threats to your health at the earliest possible time.

Testing positive for HIV can also cause you problems. People in general don't know the facts about AIDS and the condition still carries a stigma. You may face discrimination. People have lost jobs, housing and social standing after testing positive. You may find it impossible to obtain extended health or life insurance. Many countries still refuse to let persons with HIV cross their borders. While you are basically protected under the Canadian Charter of Rights and Freedoms and through provincial Human Rights legislation, exercising your rights can still be difficult and time-consuming.

Whether you test HIV negative or positive, it is important to learn as much as you can about HIV and AIDS. Transmission of the virus is easily prevented by following a few, simple rules. If you are HIV positive, you will find knowledge the key to maintaining your health and well-being.

Taking the Test

There are certain types of care you should expect when you are tested for HIV. You can be tested at a number of different places; choose one that will take care of your needs. The key component in good testing is counselling. Before you sign anything or agree to be tested, someone should explain to you exactly what is happening. This counselling should include information on the test itself, what the results mean and what they don't, and how long you will have to wait for results. You should expect to be asked both medical and lifestyle questions, the kind of questions which allow the counsellor to give you the kind of information you need. Finally, you should have to come back in person to obtain the results. Whether you test positive or negative for antibodies to HIV, you are likely to have a number of questions and may experience an emotional reaction on hearing the result. You should feel comfortable with the counsellor and you should trust the environment and the advice.

Testing Through Your Doctor

If your doctor knows about AIDS and HIV infection, you may decide to take the test as part of a general medical examination. This method will get the results to you comparatively quickly and you can deal with them as part of your overall medical care. This may be particularly important if your test results are positive, as your doctor will continue treating you for your condition. The problem with taking the test through your doctor's office is that the results become part of your medical record. As such, they may be available to anyone who would treat you medically in the future. Under certain circumstances, your medical records can also be made available to public health officials. Such reporting is not usual in British Columbia, but it is not forbidden by law. If you decide to take the test through your doctor, find one you feel you can trust.

Donating Blood

If you give blood, your blood will automatically be tested for HIV. If the test is positive, the Red Cross will contact you, probably over the phone, and tell you the results. In Ontario, the names of blood donors who are HIV positive are reported to the Medical Officer of Health because the Red Cross Blood Transfusion Service is not allowed to counsel donors. In British Columbia, no such reporting takes place. In B.C., you can donate blood if you are positive for HIV and write on the form that the blood is to be discarded. This allows you to confidentially and responsibly take part in group blood donations, say through work, without revealing your status.

Provincial Clinics

There are secure, confidential places to test your HIV status in both Vancouver and Victoria. The provincial Department of Health operates testing facilities in Vancouver through the Sexually Transmitted Disease (STD) Clinic and in Victoria through the Capital Regional District (CDR) Clinic. Both have good counselling services and operate with complete confidentiality. Community Health Nurses in many public health units throughout the province are also skilled in testing and counselling.

You must make an appointment in order to take the test (they will ask you your first name only); it is rarely possible to simply walk-in. You will initially be asked to fill in a brief form and to read some general information on HIV and AIDS. Before you take the test, you will meet with a staff nurse who will explain the test to you, ask you your reasons for taking it, and give you any information you might need or want to make an informed decision. Once you decide to take the tests (both the ELISA and Western blot are used), you will choose a code number and all further documentation will be identified by that number only. There is a double-check code which must also be used to obtain any results from your records. The nurse will proceed to

draw blood for the tests and then make an appointment for two weeks later, when you will be told the results.

When you return two weeks later, you will meet the same nurse. You will be asked about your general well-being and whether you have any questions before learning your results. In order to receive the results, you must give the nurse both codes. Then, and only then, will you be given the results. Whether the test results are negative or positive, the nurse will give you further counselling. You will be given information on safe sex, and on other ways to avoid infection. If you test positive, the nurse will give you a general explanation of what that means, and then will refer you to appropriate locations for further services, more information and care. Do not be afraid to ask questions. The clinic is there to help you. You can rest assured that your results will remain confidential under any and all circumstances.

B. TESTING HIV POSITIVE

Testing HIV positive changes your life forever. No matter how much counselling you receive right now, you will probably be confused by the lack of concrete information about HIV infection and frightened at the dismal belief: HIV+ = AIDS = DEATH.

Testing HIV positive does not mean you have AIDS. AIDS is diagnosed when a person has one of a medically agreed list of conditions associated with damage to the immune system, such as Pneumocystis Carinii Pneumonia (PCP) an otherwise rare form of pneumonia, or the reddish-purple blotches of Kaposi's Sarcoma (KS). Testing positive for HIV means only that you have been exposed to the HIV virus and you may have no obvious symptoms for periods of many months or years. The virus tends to be a long term infection that slowly weakens the human body's natural defense system. As the immune system becomes increasingly powerless, various problems can and do arise for varying lengths of time.

AIDS is a syndrome - a collection of things going wrong - and it poses unique problems for each individual. Almost all infections are treatable. HIV positive people have the advantage of the time and ability to work on preventable health steps.

You may also have heard people refer to AIDS Related Complex or ARC as a stage in HIV disease. ARC refers to a point at which you have certain symptoms but not others - sort of a pre-AIDS. It is increasingly felt that the term ARC is neither useful nor descriptive. Therefore, we will not refer to ARC in this manual and you will mainly find it only in earlier writing. For ARC, simply substitute HIV infection. Remember, even if you have the symptoms described under ARC, you do not have AIDS.

C. NOW WHAT?

Being told you are HIV positive may not be a surprise to you; you may have been suspecting it all along. Or it can come like a bolt from the blue. It can even come as a relief, especially if you have been ill but no one has been able to tell you exactly why. Nonetheless, you're likely to feel shock when your doctor confirms you are HIV positive or that you have AIDS. "This can't be happening to me!" is a common response. You may be surprised at how little you actually feel, as if you were overcome with emotional numbness. This feeling of shock can last a long time.

You may find yourself denying what's happening. What do doctors know? Why are people so worried about me when I feel fine? AIDS! I'm not going to let it change my life! You may make plans that turn out to be unrealistic for you, or tell people you're not really upset by the diagnosis.

You may feel angry. You may be upset with the doctor who didn't prepare you enough for the diagnosis, with indifferent health care professionals, with governments who drag their heels on funding for AIDS research. You may be angry at God, at the person who "gave you" AIDS/HIV, or at other people for being healthier than you are, even healthier PWA/HIVs. You may feel frightened by your rage or your outbursts of temper.

It's also common to have thoughts about your own death. When will it happen? How will it happen? Will I be in pain? Will I be a "vegetable"? What about euthanasia? You may even feel suicidal.

And you may feel confused. Why am I behaving this way? Am I going crazy?

All of these feelings are common and normal. Other PWA/HIVs also deal with anger, depression and confusion. Don't worry if these emotions continue for some time or if you find yourself unable to remember much of what the doctor has told you. Many others have had the same experience.

A good start to coping with AIDS/HIV is to realize that you are not at the mercy of the virus, doctors, chemists, the government, family, friends or lovers. While you will have to deal with many or all of these people, you will still - maybe more than ever - want to make your own decisions. The key to maintaining that control is knowledge.

While many questions remain about AIDS and HIV infection, a great deal is now known. And there are many good ways to become informed. This manual will answer your basic questions, but there will be a number of areas where you will want to know more. The Vancouver Persons With AIDS Society, AIDS Vancouver, AIDS Vancouver Island and other BC community AIDS groups have a wealth of information on all aspects of HIV infection and AIDS; their services and libraries are there for you to use. You should also feel free to ask questions, questions and

more questions. The answers will give you a better understanding of what you are dealing with. The people you talk with will also be able to give you much-needed support.

D. SOMEONE TO TALK TO

One of the hardest things you may face is feeling isolated, that you are completely alone in coping with the diagnosis. However you don't have to be ready to talk with your family or friends to reach out for help and understanding.

Other PWA/HIVs

Other PWA/HIVs have had experiences like yours and they understand what you are trying to cope with. You may not really grasp what your diagnosis means, and doctors don't always have the time or the desire to explain everything thoroughly. Other PWA/HIVs can tell you what to expect, especially when it comes to dealing with infections you may get, or reactions to certain drugs. They can give you tips on how to handle particular health problems, and can share information on symptoms and treatment. They can be there for you emotionally. As you share with other PWA/HIVs, you will begin to realize that you are not alone.

Joining a support group for PWA/HIVs can help, even if you're not a "group" person. So can finding another PWA/HIV you can talk with. One PWA dealt with his initial diagnosis by going for a walk every day with another PWA, one who had been coping with AIDS for a longer period of time. He found it helped to talk to someone who had "been through it", while exercising at the same time.

Counselling

The time may come when you will need more help or support than a friend or another PWA/HIV can offer. Hard as it can be to admit that you're in trouble, don't pretend everything is fine if it isn't. It takes courage to deal with fear and uncertainty. And there are professional counsellors who can help you along this very confusing path.

Finding the right counsellor may take a bit of research. Your doctors or nurses can give you good suggestions. You can check with AIDS organizations, with other PWA/HIVs, or with friends. You will want a counsellor who understands AIDS and HIV infection, so talk to a few over the phone before you actually make an appointment. A good counsellor will support this kind of research.

Counsellors usually schedule the first appointment as a sort of "getting to know you" session. This allows both of you to decide if you can work together before making a major commitment

of either time or money. Counselling can only help if you feel comfortable with the person you are talking to. If you don't feel right with this person, try again. The choice is up to you.

Depending on your health insurance, you may have to pay for counselling. Psychiatrists are automatically covered by B.C. medical as long as you are referred by your doctor but in general, you must pay for psychologists, counsellors and other therapists. There are counsellors who will base their fees on what you can afford, so again, shop around. You can also obtain counselling through community groups such as AIDS Vancouver and AIDS Vancouver Island, or attend support groups through the Positive Women's Network. And you can talk with peer counsellors, all of whom have AIDS or are HIV positive, through the Vancouver PWA Society.

The important thing to remember is if you need help, get help.

E. FEAR OF AIDS

The idea of AIDS is frightening to many people. As someone affected by AIDS/HIV, you may come face to face with prejudice and condemnation around this condition. Too many people still don't understand how the virus is spread, and a social stigma is still attached to many of the groups who have been most affected. In the public mind, AIDS is associated with gay men, drug addicts and prostitutes, groups which are seen as outside the "norm" and as such, are feared and stereotyped. Add to this the misconception that HIV is easily spread, and it creates a feeling of great danger around AIDS and HIV.

It may help to realize that the stigma attached to AIDS comes from people's fears, not their reason. For your own emotional protection, it will be important that you distinguish between the kind of prejudice it is better to ignore, and the kind of misinformation which is open to correction. However, do not feel it is up to you to reform the world's attitude about AIDS and HIV infection. Anything that touches on sex or death raises issues for people that they may prefer to ignore. They will need to choose to deal with their own fears before they will be able to cope with your more reasoned approach.

If you are gay, you may also have to deal with homophobia, the fear and hatred of gays and lesbians. This is a very difficult issue for it can involve not only other people's homophobia, but also internalized prejudices you have picked up from the rest of society. For you, this may set you wondering what you have done "wrong" to "deserve" AIDS, or wishing you weren't gay, or feeling bad about yourself in other ways.

It is difficult at times not to wonder about these underlying questions, particularly as they raise so many of the same issues you faced in initially "coming out". This problem is not made easier by the perception that homophobia is a "socially acceptable" prejudice in our society. For all the understanding you may receive from family and friends, many of whom are "straight", too many institutions still feel at liberty to discriminate on the basis of sexual orientation. Churches

do refuse to accept gay men and women for the priesthood, and school boards do fire gay teachers.

The high profile of the AIDS epidemic has made people much more aware of homosexuality. Sometimes the effect has been good, bringing more understanding and breaking down stereotypes. Unfortunately, at other times it has brought people's prejudices more to the surface and provided a whole new arena for anti-gay activities.

There are things you can do about homophobia and the fear of AIDS. The Vancouver PWA Society, AIDS Vancouver and AIDS Vancouver Island can help with reading material which will let you see your personal feelings in the context of what is going on in society as a whole. If you are gay, it may help to find gay men or women to talk with, or to read accounts of other gay people's lives. Other PWA/HIVs have also dealt with these issues and it may prove helpful to share your concerns with them.

You are a worthwhile and valuable person. As others learn the facts as opposed to the myths about AIDS and HIV infection, their understanding of your condition will increase. In the meantime, be true to who you are in coming to terms with your own needs.

F. WHO TO TELL

When you are diagnosed, you may be uncertain about who you should tell. You will probably want to share your concerns with those you are close to, but you may find yourself worried about their reactions.

There are no hard and fast rules on who to tell. The best thing you can do is to follow your own instincts and share with those you trust and feel good about. Initially, you may choose to tell only your lover and closest friends or family, perhaps only one or two people. As time passes and you become more used to dealing with your condition, you may wish to tell others. Keeping things to yourself for a while gives you more choice. You can always tell people later, but you can never reverse the situation once you have let people know.

Remember, you can't predict how people will react when you tell them you have HIV or AIDS. People who would be supportive and understanding under any other circumstances, may react in ways that seem out of character. You may feel quite vulnerable for a while and if you are in doubt, you are probably wiser to protect yourself. You can exercise caution and simply choose to tell only those you trust. There are, however, certain things you can keep in mind in making these decisions:

YOUR LOVER OR PARTNER: This person should be told as soon as possible. You will want their support and the news has implications for their health. Hard as this may be to do, waiting will only make things more difficult. If they are willing and you want to, you can also

include them in discussions with your doctor and counsellor. This can make it easier for both of you to share information and support.

FRIENDS: When you are first diagnosed, it can be very valuable to tell one or two close friends. It may make sense to wait and make sure before sharing your status with less close friends and acquaintances. When you do tell friends, make it clear that you wish them to respect your confidentiality. If they can't keep quiet, don't tell them.

LANDLORD: Due to the current misunderstanding of issues around AIDS and HIV infection, you are probably wiser not to tell your landlord for the time being. Your landlord does not need to know. Unfavourable reactions could affect your housing situation and you don't need additional problems or stress at this time.

NEIGHBOURS: Again, neighbours can cause problems for you if they know your status. Unless they are close friends, it is probably better not to talk with them about your condition.

EMPLOYER AND FELLOW WORKERS: There is no reason for you to tell anyone at work. People with AIDS and HIV infection have lost jobs through trusting the wrong person, and while you do have protection under B.C. Human Rights legislation (see Chapter 2), you again open yourself up to unneeded stress.

In general, exercise caution and tell people only when you feel you are ready to do so. Trust your own instincts and your own sense of when the timing is ok.

G. TELLING YOUR FAMILY

Whether or not to tell your family immediately about your condition depends entirely on your relationship with them. If you are comfortable with the idea and feel that they will be supportive, you may be wise to tell them immediately. On the other hand, if you feel the news may be difficult or stressful for them to handle, you may choose not to tell them for the time being.

Do not rush into telling them until you are sure that this is what you want to do. You are really the best judge of how they will react. You know your family better than anyone else does.

If you acquired AIDS/HIV through a lifestyle choice your parents are unaware of, this may present a further consideration in how and when to tell them. Whether you have been having unprotected sex, gay or straight, or sharing needles, this confession may add further stress to

an already difficult situation. Again, trust your own sense of what is right to do under these circumstances.

Any unresolved issues you have with your family are likely to arise when you discuss your condition. Because they are family, you may want to consider how they are likely to feel if you choose not to tell them. You may worry that your family will find out eventually no matter what they are told. It can be very difficult to conceal an illness from them if they are determined to know the truth.

It is important that you make the decision you feel is best. If your family will be loving and supportive, they will make your life with this condition much easier. They may be able to help with housing or financial assistance. Sharing your concerns with them may also lead to a very strong, supportive relationship. On the other hand, if your family will only add further stress to your life, you may choose to keep your condition to yourself. This is your right, and only you are responsible for what you finally decide.

H. DEALING WITH FEAR AND DEPRESSION

Attacks of fear and depression are completely normal and may occur from time to time. You may worry about the effect of the diagnosis on those around you. Concerns arise around the possibility of going into hospital or the fear of losing control of your life. You may simply have a general sense of anxiety coming out as negative thoughts or feelings of hopelessness.

Try not to let these periods of fear and depression take control of your life. If you find yourself unable to cope or if the depression lasts more than a few days, you may be wise to seek professional help. In a bad period, a doctor can give you anti-depressant drugs which may help over the short term.

During these difficult times, you may find yourself thinking about suicide. This is a personal decision, but one you should consider carefully and preferably talk over with a counsellor, close friend or another PWA/HIV. It is important to remember that a diagnosis of HIV infection or even AIDS is not a death sentence. HIV positive status does not guarantee you will develop AIDS. Even if you are diagnosed with AIDS, treatments are being developed all the time which deal effectively with the associated diseases and infections. There are now documented cases of people who have lived with AIDS for over eight years and are still going.

You should also keep in mind that you may feel quite different tomorrow or next week. Your depression may lift or your circumstances may change. It is also important to consider the effect of suicide on your friends and loved ones - it could be devastating for them. This is one decision that cannot be reconsidered. There are a number of PWA/HIVs who have contemplated suicide and later been very glad they chose not to do so.

If you find yourself experiencing changes in mood or continuing depression, it is important you consult your doctor. These symptoms can be caused by a change in your physical condition or as a reaction to a particular therapy and may be easily relieved by medical treatment. It is always wise to talk with your doctor any time you notice a change in how you feel.

There are a number of things you can do to ease bouts of depression. Talking with someone you like and trust will usually help. Just being open about your fears will often make them seem easier to handle. When you feel down, it's also a good idea to indulge yourself, to do things you particularly like to do or to pamper yourself somehow. Maybe you have a special food you love, or you always feel better when you buy a new shirt. Now is the time to treat yourself to whatever works for you.

Exercise can go a long way to helping you feel better. Even just a walk in the fresh air can help. There are also relaxation techniques, such as visualisation, yoga or meditation which are wonderful for relieving stress and depression (See Chapter 6). No one technique will work for everyone, so you may have to experiment a bit.

Be very aware of the spiral of depression. This occurs when one negative thought leads to another which is even worse. You will have to find some way to break that chain, whether it is going dancing, reading a special book, taking in a movie, or talking with a friend. Also beware of withdrawal, of pulling away from things you enjoy doing. If you enjoyed doing them before the diagnosis, you will still enjoy doing them after.

This is not an easy time, but it can be a very fulfilling one. Find things you like to do and then do them.

I. HOPE AND THE FUTURE

At some point in coming to terms with a diagnosis of AIDS/HIV, you will probably ask your doctor, "How long will I live?". There is no answer to this question for the length of anyone's life is unknown. HIV infection is complex, basically slow-moving, and still very unpredictable. Even statistical estimates on life expectancy of AIDS patients with particular infections are only averages and are essentially meaningless for an individual. NO ONE KNOWS what is going to happen, how long we are going to live, or how we will die. This is true for everyone and people with AIDS and HIV infection are no exception.

Understanding of, and therapy for, this condition are also rapidly changing. Huge amounts of money are now being poured into the search for both treatments and a cure. Pharmaceutical companies continue to work on developing new drugs and a number of promising experimental drug trials are now underway. In the meantime, treatments for the opportunistic infections associated with AIDS and HIV infection are becoming more sophisticated and effective. There are good reasons to believe that AIDS/HIV will, in the near future, be managed as a chronic condition.

In the meantime, living with a diagnosis of AIDS/HIV can cause you a great deal of stress. You may feel confusion and anxiety about your diagnosis or have to cope with certain changes in your lifestyle. Some stress is inevitable and you will be wise to learn to deal with the stress that you can't avoid. There are numerous resource books and tapes on stress reduction techniques and approaches to positive living. Other PWA/HIVs can also help with ideas on reducing stress. Through trial and error, you can figure out what will work best for you.

You will also find that taking an active role in your own health care will help you feel better about yourself and more in control of your life. You can do this by reading and learning about AIDS and HIV infection, and by finding out who can help you and how you can help yourself. With this information, you will be in a position to make your own decisions and to chart your own course, becoming an equal partner in maintaining your health and welfare.

Try not to take on the victim or invalid role. Seeing yourself as a victim can reinforce any feelings of helplessness you may have. The more someone feels they are an invalid, the more likely they are to become one. If you feel this way, try talking it through with a friend, another PWA/HIV, or a counsellor. Probably the best thing you can do to counteract this tendency is to take positive steps towards participating in your own health care and controlling your own life.

Be good to yourself. It can be nice right now to indulge yourself a little - or a lot! You may have to put yourself out less for others and give more to yourself, or protect yourself from other people's demands in some ways. Admit that you don't have enough energy for everything, and that others may feel disappointed with your choices at times. If they care, they will understand. Your health and wellbeing are your number one priorities.

It's important now to make time to cultivate close friends. Loneliness is always a problem, but may be particularly so if you have a diagnosis of AIDS/HIV. You will need friends to trust and be intimate with. This may prove particularly difficult if you know no one else in your circle who is dealing with this condition. There are a number of groups now running for PWA/HIVs in similar situations; you can get more information on where to meet others dealing with issues similar to yours through the Vancouver Persons With AIDS Society. It is certainly better to find a counsellor or another PWA/HIV to confide in than to carry the weight of your diagnosis on your own.

Probably the most important thing you can do for yourself at this time is to develop a positive attitude towards yourself and your life. There are documented theories about the connection between a person's emotional state and their physical health, and many examples to show that the connection is strong. Long term survivors - people who are living with AIDS and HIV infection - are invariably people who feel good about themselves and their lives. This doesn't mean that you shouldn't feel sadness, anger or despair. Or that you shouldn't cry or be depressed. These feelings are normal and to be expected; the more open you are in expressing them, the healthier you will remain. Expressing all of who you are, developing as much of a positive attitude towards your life as you can, in the long run may turn out to be your best treatment.

CHAPTER TWO: ANYONE CAN GET AIDS

A. INTRODUCTION

AIDS is a syndrome, a complex collection of opportunistic infections which arise as a result of a depleted immune system. Medically it has no single face, affecting individuals in surprising individual ways. Over twenty-five specific diseases are now used to diagnose "AIDS" and many of these same diseases can also arise in the absence of HIV infection. There is no way to predict how or when the virus will affect any particular person.

Personal circumstances play a large part in many aspects of your life with AIDS/HIV, and a number of these issues have only recently begun to receive wide acknowledgement. The major reason for this omission is the continuing perception of AIDS as a "gay disease". The perception has more to do with history than current reality.

AIDS arose in North America during the early 1980s primarily in the gay male community and for the first few years of the epidemic, it remained mainly a "gay disease", at least in terms of the numbers of recorded AIDS cases. The virus has long since spread into virtually all "groups" within North America - heterosexual, homosexual and bisexual; men and women; all ages, all races, and all socio-economic classes. It has spread via sexual transmission, through blood products, by shared needles, and from mother to foetus. HIV is no respecter of persons and spreads when given an opportunity to do so.

As people, we are complex and we do not fit into neat categories. Nonetheless, outlining issues by category can be helpful in determining how to get your needs met. The following outline is by no means exhaustive, but it provides a beginning to finding the help you need and contacting others who share your concerns.

B. HOMOSEXUALS

Homosexual men with AIDS and HIV infection have been at the leading edge of organizing at the community level since the earliest days of the epidemic. As a result, gay men in large urban centres can access strong support networks and usually have access to knowledgeable medical care. The most extensive medical and socio-economic knowledge on the affects of living with AIDS and HIV comes from the gay community.

As anyone in the gay community already knows, homosexuals face many problems, particularly discrimination, in dealing with the world at large. These problems have been exacerbated by the prevalence of AIDS and HIV infection within the community, and have led to attendant discrimination against people testing HIV antibody-positive.

This prejudice against gays has led to problems for many with AIDS and HIV who live outside of large urban centres and cannot easily access knowledgeable medical care. Simply declaring their status, a difficult process in an environment where gays are not accepted, can place a

person with AIDS/HIV in an impossible social position. Further, medical personnel in smaller centres are only now beginning to become knowledgeable about the syndrome, and are by no means up to date on current discoveries and treatment trends. Simple procedures such as accessing blood tests may require travelling many miles.

Nonetheless, the problems gays face in dealing with AIDS and HIV discrimination are generally the problems they face in being gay. Medically, they can be reasonably assured that whatever is known about dealing with the syndrome will apply to them.

Lesbians face much the same discrimination faced by gay men, compounded by the still minimal knowledge about the affects of AIDS and HIV on women. Lesbians face a further problem because of the still widely-held belief that they do not become infected with the virus, despite cases proving that they do. There does seem to be some evidence that lesbian sex is less dangerous *per se* than sex involving penis penetration, but any exchange of bodily fluids can in theory be risky. The medical problems faced by both lesbians, heterosexual and bisexual women are outlined in Chapter Eight, "WOMEN, CHILDREN AND AIDS".

C. HETEROSEXUALS

Heterosexual men theoretically have access to the same level of medical care and knowledge that is available to homosexual men. Practically, internal and external fear and discrimination against gays, and correspondingly those with AIDS and HIV infection, present enormous barriers for heterosexual men. "Straight" men do not tend to access community services available for people living with AIDS and HIV, feeling they will be seen as gay by walking in the door. In general, they are less likely to raise questions about their medical care, and are more likely to have physicians who are less knowledgeable about the syndrome.

This situation is changing to some extent, as the virus spreads into the general population. Nonetheless, straight men must usually overcome self-imposed isolation before they can access the care, knowledge and support that is available.

Heterosexual women face many of the same problems faced by lesbians, compounded by the same sense of isolation faced by heterosexual men. They live in a very difficult situation, often afraid to tell their friends and family about their condition, dealing with medical personnel who may know little about AIDS and HIV infection in general and less about its affects on women, worried about what will happen to their children, and generally lacking support from other women facing the same condition. Like straight men, overcoming self-imposed isolation will be the first challenge to accessing care, knowledge and support.

D. BISEXUALS

Bisexual men and women face certain levels of discrimination from both heterosexual and homosexual communities. Understanding and acceptance of bisexuals is only beginning, and many will feel uncomfortable revealing the other side of their nature to the community they primarily identify with. This can be as true for the husband with an occasional male lover as for the lesbian who occasionally has relationships with men or the gay man who has a female lover at times. In terms of dealing with AIDS and HIV issues, the key determinant to the person's access to care and support will probably be the level of knowledge and openness about the virus within the person's primary community.

If you are trying to cope with bisexuality, particularly tied to a diagnosis of AIDS/HIV, you may find benefit in joining one of the few bisexual support groups which now exist. For more information, a good place to start is contacting the Gay & Lesbian Community Centre in Vancouver.

E. HEMOPHILIA

The following was written by Rick Waines, who coordinates Peer Support within the Canadian Hemophilia Society:

"A lot has been said in regards to the differences between someone who has been exposed to HIV through blood products and people who have been exposed to HIV through other modes of transmission. Let it be said once and for all that, with the exception that KS (Kaposi's Sarcoma - a form of cancer) occurs rarely in the person with hemophilia, there is no difference.

A person with hemophilia is no different than anyone else who is HIV+. We all experience the same sadness, the same loss, and the same pain. A person with hemophilia is often judged to be different because they have family and dependents. There is no difference. Everyone has family and people who depend on them emotionally, physically and financially.

The virus makes no distinctions. No one asked to be infected and no one wants AIDS/HIV. We are all living with the same situation and plan to go on living with the same situation for a long time to come."

The major challenge for a PWA/HIV with hemophilia will be finding a physician who is familiar with both conditions. Many doctors who have treated hemophilia for some time are now keeping abreast of the manifestations of HIV, and this need is becoming easier to meet. If you need advice or medical referrals, contact the Hemophiliac Assessment Clinic at 895 West 10th

Avenue, Vancouver (879-7511) or the BC Chapter of the Canadian Hemophilia Society at 3998 Main Street (873-3666).

F. AIDS AND HIV ON THE STREET

There is a growing prevalence of AIDS and HIV infection among people who live "on the street", generally those with few financial resources and frequently underdeveloped social skills. These people face challenges beyond those created by dealing with the virus and often must take extra steps, and access extra support, to maintain their health.

The following article was written by Frank Smith, who tested HIV antibody positive when he was still "on the street":

"Being on the street can be stressful enough, but with the news that you are HIV+ or have AIDS, that stress rises considerably. Most importantly, **DO NOT PANIC**. You must keep your wits about you if you are going to survive.

Ask yourself some questions: Do you have a place to live? Is it clean and fairly quiet, or is it a noisy "Roach Hotel" where you cannot sleep very well? Rest is very important. Your worker must find you a healthy place to live.

Do you have medical coverage? Ask your worker to apply for medical benefits for you. Your worker will issue you a s430(87/06) until your BC Care Card arrives. You must have a note from your doctor (on letterhead) stating that you are HIV+. Also, have your doctor write a note stating that you need the Dietary Supplement and the Bus Pass Allowance. Remember, if you have trouble with your worker, there are people who will help you.

You should also request the Handicapped Form and the booklet for your doctor called 'GAIN for the Handicapped: How to Apply'. Make sure you get this booklet as it will explain to your doctor how to fill out the form. Many doctors do not understand this form because of the wording of the questions. This form is not made for HIV+/AIDS persons.

It will take 4 - 8 weeks for your request to be approved. Your worker should classify you as "unemployable" until you hear back from the committee. Remember you have the right to appeal and help is available for you to do so.

If you have a chemical or alcohol problem, you should consider what effect this will have on your health and whether you want to continue using or not. Again, help is available.

If you need someone to talk to, there are support groups and one-to-one counselling available.

If you are under 19 you may become a Child In Care (CIC). You have the right to healthy shelter, food, clothing and medical care. You have the right to advocacy (help in exercising your rights and getting service) and appeal. If you are 16 or over, you have the right to make your own medical decisions. As you approach 19, you should have your worker make sure that you are set up for your handicapped benefits.

Remember, you have the right to know what is happening to you. You have the power to keep control of your life."

The Street Project:

A specific support program has recently begun in Vancouver for street involved people who have AIDS/HIV or who are at high risk for HIV infection. The Street Project offers counselling and therapy to street involved youth and intravenous drug users, as well as to partners, friends and family. The project also provides information, support and consultation to other caregivers who work directly with this client group. Full confidentiality is a must and the project staff insist that the client choose when, how and to whom to disclose any and all issues.

The project is located at 213 Main Street in Vancouver's Downtown Eastside and will provide service to the Mount Pleasant and West End area upon appointment.

G. SUBSTANCE USERS

The following information was provided by the Vancouver Needle Exchange and Vancouver's Street Project:

Prevention:

The success of the Vancouver Needle Exchange has proven that the prime strategy in prevention as a substance user is not to share filters, works, washing, cookers etc. with anyone. Injection drug users in Vancouver now have among the lowest HIV conversions in North America, a clear demonstration that this strategy works. Not sharing with others also means you won't spread the infection if you already have it.

Dealing With The Test Results:

The most important first step you can take after testing positive is to get help in dealing with the shock and denial as soon as possible. This is a particularly vulnerable time, one made more difficult if you have tended to use drugs to deal with your emotions and your problems. The problems you face in coming to terms with AIDS/HIV will only become more difficult if you don't deal with them straight on. The fact that you got the virus or may have given it to someone else can also become a real guilt trip. The reality is anyone can get the disease.

Although you may not feel any different right now, your health can change if you pay attention to your body's needs. Drugs, late nights, not eating properly create real problems for your immune system. Long-term survivors with AIDS and HIV infection tend to last because they look after themselves. They get more sleep, cut down on or cut out substances, eat two or three balanced meals a day, and take advantage of the services available to help them.

There are people who can help you deal with denial, anger, and depression. If you can't afford food or don't have somewhere to live, there are people who can help you with these as well. If you don't know where to begin, talk with the Street Project, the Needle Exchange, the Vancouver PWA Society, AIDS Vancouver or AIDS Vancouver Island. Someone will be able to help. The most important thing for you is to act now - your immune system needs attention.

You can add years to your life just by taking a few simple steps:

1. **Figuring out what you have to do:**
Get help in sorting out your situation, dealing with your emotions, and deciding what to do next.
2. **Dealing with your emotions:**
Get counselling. Talk to someone at the Needle Exchange or the Street Project who knows what you're dealing with.
3. **Dealing with drugs:**
Try to get off the drugs and into a substance abuse program. You can't do two or three day coke runs and expect your immune system to get better.
4. **Medical care:**
Find a doctor or a clinic that knows about AIDS and HIV and then work with them to keep yourself healthy.
5. **Money:**
Make sure you can get the money you need to support yourself. You're entitled to more than just regular GAIN. Then work out a budget to make sure you don't run out of money before the end of the month. You can get help to sort this out as well.

6. **Getting healthy:**
Decide how you can keep healthy. Work out how to get regular meals and make sure you have a proper place to sleep. Get help if you're having trouble making this work.
7. **Take the whole thing day by day:**
You don't need to do everything all at once. Just take it a step at a time. And don't worry if you fall back a bit. Just don't give up. Keep trying.

More Prevention:

Protect yourself from colds, flu, and anything else. You can do this mainly by taking care of yourself and keeping your immune system as strong as possible. It is also extremely important that you practice safe sex at all times, and never share needles, works, etc. This is crucial for two reasons. First, this way you don't pass on the virus to anyone else. Second, you don't catch anything from anybody else. Remember, your immune system can't fight off infection easily. It needs all the help it can get from you.

Help is Available:

You don't have to deal with this by yourself. The people at the Needle Exchange know what you're dealing with and they can give you good advice on how to find what you need. The Street Project is also good, and they have peer counsellors, others like you who have AIDS or HIV and know about living on the street.

The Vancouver PWA (Persons With AIDS) Society provides a lot of programs and support. They can give you information about drugs, doctors, housing, GAIN, and can help you protect your rights. You will find when you get there that many street people are members and use the services there quite often. The Vancouver Native Health Society is a good place for help and support if you are aboriginal. You can also get help and information from both AIDS Vancouver and AIDS Vancouver Island.

H. NATIVE HEALTH

Aboriginals dealing with AIDS and HIV infection will face different problems depending on where they live. Those who live in rural areas, may have problems accessing knowledgeable medical care, appropriate blood tests, etc., and may feel isolated within the community. The issues faced by Natives in urban areas depend on their lifestyles and circumstances, frequently compounded by racism.

In general, knowledge of the affects of AIDS and HIV within Aboriginal communities is growing as the infection itself spreads. If you are Native and are seeking services, your best

contact will be the Vancouver Native Health Centre, a very new comprehensive facility which incorporates all facets of Native healthcare from conventional care and counselling to Traditional Healing and holistic medicine. Plans are for the Facility to house units for medical, dental, pharmaceutical, Traditional Healing, nutrition programs, alcohol and drug programs, health education and promotion, outreach clinical and counselling services. An AIDS Program will be included and will address counselling and housing issues. You can reach the Vancouver Native Health Society at 254-9949.

For further information, you can also contact the Native Health Department, Ministry of Health, in Victoria (356-7090), or the Vancouver Native Health Project at 685-8260.

CHAPTER THREE: SUPPORTING YOURSELF

A. PROTECTING YOUR RIGHTS

Testing positive for HIV raises not only medical and emotional issues but also some very practical considerations. As long as you have no symptoms or few symptoms, you'll probably continue working at the same job and living in the same place. Should you develop symptoms or become ill, you may decide to make some changes. There are certain issues to consider in making those decisions, and we'll talk about these later in the chapter.

You should be free to work and live where you choose. However, people do discriminate against individuals with AIDS and HIV infection. To keep control over these areas in your life, it is important you know your rights. Human rights legislation applies to many areas of your life, including work, service and housing. There can be exceptions and the lines drawn between areas are by no means clear. It's not always easy to figure out where you're protected.

Current human rights legislation across Canada does not specifically protect an individual against discrimination on the basis of HIV status. This is not to say that you are not protected under the various human rights codes but, because the protection falls under other more general areas, it is uneven. One key problem is that discrimination on the basis of sexual orientation is not prohibited under human rights statutes in seven out of ten provinces (including B.C.), nor is it prohibited under the Canadian Human Rights Act. This means that, except in Manitoba, Ontario, Quebec and where protected by specific municipalities or employers, you can be treated unfairly because you are homosexual, whether or not you are HIV positive. This gap could mean that you would have to prove any discrimination occurred because of your HIV status and not because you are gay.

It is argued that existing human rights legislation in Canada protects persons with AIDS and HIV infection because their condition falls under the classification of "illness" or "disability", terms which are used in some form in all federal and provincial human rights codes. All complaints of discrimination on the basis of HIV status filed to this date have fallen under one of those two headings. While these categories seem to afford fairly clear protection, they still do not cover all situations.

To begin with, while AIDS and HIV infection would appear to fall within the meaning of illness or disability, it is not absolutely clear that this category includes people with HIV infection who have no symptoms. The degree of discrimination that is judged to be justified also varies from jurisdiction to jurisdiction. For example, the Canadian Human Rights Commission allows discrimination in employment on the basis of AIDS and HIV infection on three grounds:

- (1) the employee must carry out invasive procedures as an unavoidable part of their work;
- (2) the employee must travel to countries which bar entry to people who test positive for the HIV virus; and

- (3) the employee works in a job where the sudden deterioration of the brain would compromise essential safety requirements.

The Ontario Human Rights Commission, on the other hand, allows discrimination in employment on the basis of AIDS and HIV infection only when the employee would need to travel to countries which bar entry to people who test positive for the HIV virus. In British Columbia, reasons to allow discrimination on the basis of AIDS and HIV infection are not defined *per se* but are dealt with on a case by case basis. In general, it would be allowed only if your health limited your ability to do the core elements of your job.

Issues affecting individuals with AIDS and HIV infection and those who are members of perceived "risk groups" but don't have or don't know if they have contracted the HIV virus, have been debated by the Canadian Human Rights Commission which has recognized the rights of these individuals and has recently developed guidelines extending protection to family members, friends and others who associate with HIV infected people.

In British Columbia, the B.C. Council of Human Rights has judged that anyone testing positive for antibodies to HIV has a physical disability under the Act and, in the absence of an occupational requirement, is entitled to the protection under the Act. This protection is extended to so-called "high risk" groups who are not HIV infected or whose HIV status is unknown, as well as family members, friends and others who associate with those who are HIV positive. While guidelines and decisions have widened the meaning of "disability" to include HIV infection, it is still not specifically illegal to discriminate on the basis of HIV status.

If you feel that your rights are being violated, you can file a "complaint form", which is available through the B.C. Council of Human Rights. Office locations are listed under Government of B.C., Human Rights Complaints in the blue pages of the phone book. You can drop into the offices for a form, or they will send you one if you phone them. The forms are also available at any Employment Standards Branch office in the province. Your local Legal Services Society (legal aid) office, may be able to provide you with legal assistance, even if you do not qualify for legal aid. Free summary legal advice is available through a drop-in Gay/Lesbian Legal Advice Clinic at the Gay/Lesbian Community Centre in Vancouver.

No matter how well your rights may be protected under Human Rights legislation, the time it takes to reach a judgement once you have filed a complaint creates another barrier to fair treatment. A hearing can take place within six months; it has been known to take up to two years. In British Columbia, it takes an average of 12 to 18 months. To date, most cases have been settled through negotiation or mediation. While this process has avoided long, drawn-out arguments, it has not produced satisfactory solutions in a number of cases. The B.C. Council of Human Rights also attempts to mediate a solution wherever possible and they have reached settlements in most cases in favour of those discriminated against on the basis of HIV status.

The single complaint to proceed under federal human rights legislation recently resulted in an award of \$25,000 to a cook who was fired from a railway road gang because he was HIV positive. This ruling marked the first time job rights of a person with AIDS/HIV had been fully

tested before a federal tribunal. While this decision covers only the 10 per cent of workers employed by the federal government or its agencies or under federal regulation, the ruling is expected to influence provincial human rights tribunals which cover the other 90 per cent of the work force. In this case, the complaint was filed in November 1987 and the judgement was handed down in October 1989.

There are other ways you can fight discrimination in the workplace. The federal government now has a written policy on AIDS in the Workplace, a policy which covers all federal employees and gives political impetus to job rights in other jurisdictions. The City of Vancouver and the Province of British Columbia have similar policies. Your company may already have a policy on AIDS and HIV in the workplace; if so, you could appeal to the personnel department or to your employer. If you belong to a union or professional association, they too may have a policy on discrimination due to AIDS/HIV status.

Fighting discrimination ends up being a difficult and very personal issue. Many people hate to make a fuss and will change jobs or apartments rather than stay and fight the prejudice. It is good to know that there are a number of ways to deal with these issues. The Vancouver Persons With AIDS Society carries on advocacy work which can help you find a solution to discrimination. There are lawyers who work in this area and legal costs can be covered through legal aid. If you choose, you can have your lawyer negotiate quietly on your behalf rather than immediately filing a public complaint.

There is, currently, very little protection of your rights when you travel. Many countries refuse entry to people testing positive for HIV. Some countries automatically test for HIV when you attempt to enter; others will only test you if they suspect you are part of a "risk group".

At present, in Canada, there is no requirement that any person entering the country for any reason be tested for HIV antibodies. However, if you have AIDS, you can be refused entry to Canada under Section 11(2) of the Immigration Act. PWA/HIV organizations around the world, in consultation with the World Health Organization, are currently working toward establishing freedom of movement for all PWA/HIVs. In the meantime, you would be wise to be very sure of the immigration and travel policies in any country you wish to enter.

Public understanding of AIDS and HIV infection and the legal protection of your rights are growing. While the changes are not yet dramatic, discrimination on the basis of AIDS/HIV status seems less likely as time goes on. This does not mean that you can assume immediate acceptance as a person with AIDS/HIV, but does give hope that you will meet less outward prejudice.

B. SHOULD YOU KEEP WORKING?

Sorting out whether to remain working or not can be difficult at best, particularly if you are not feeling completely well. There are many factors to take into account in deciding whether or not

to stay in your job. You will have to consider your financial situation and may have to weigh your emotional and physical health against your financial health. If you receive extended medical and dental benefits through work, you may wish to stay in your job for as long as possible; if you can receive a disability pension through your job, particularly if medical and dental benefits are included, leaving work may prove much less traumatic.

It may be helpful to sit down, work out exactly what your expenses are and draw up a budget. At the same time, you can sort out your financial priorities, instead of trying to deal with everything at once. AIDS Vancouver and AIDS Vancouver Island offer financial counselling, and you can get assistance from a social worker through your hospital. AIDS Vancouver might refer you to a lawyer (a donated service) for debt counselling, if this is your most urgent need. You can also obtain debt counselling through the Vancouver PWA Society or directly from the Debtors Assistance Branch of the B.C. Government, which is listed under Consumer Services in the blue pages of the phone book.

Other factors will have a place in your decision. You will probably find yourself seriously considering how much you really like what you do, how fulfilling it is, whether you like the people you spend most of your time with, and whether there is something else you'd rather be doing. If you're an accountant but have always wanted to take a year to play the violin, now may be the time to pursue that dream. In this area, as in all others, it is important that you make your own decisions for your own reasons.

It has been proven that if you keep busy, particularly if you are doing something that has meaning for you, you will remain healthier for a longer period of time. Do not ignore other areas you can make a commitment to, such as volunteering with the PWA Society or helping to organize your swim club. You may decide that the best set-up for you is to work part-time and volunteer part-time. Becoming HIV positive can be a burden, but it can also be an opportunity for you to make changes in your life that will bring you increased fulfilment and pleasure.

C. AIDS IN THE WORKPLACE

Your experience of AIDS/HIV in the workplace will be largely determined by three factors: the size and nature of your workplace, your position in the company, and your stage of illness. Certain issues that arise will depend entirely on your specific circumstances and you will have to deal with them as they come along. However there are certain questions you will probably have to consider no matter where or how you work.

The first question in the workplace, as in many other areas, is whether or not disclosing your HIV status is necessary, appropriate, or safe. This actually comprises a number of questions:

- Does anyone have to know?
- When should you disclose HIV infection?

- Why should this information be disclosed? Who will benefit?
- To whom should information be disclosed?
- Will this information be kept confidential?
- Can you lose your job because of HIV infection? Under what circumstances? What protection/recourse do you have?
- Can you be refused employment because of HIV infection? Under what circumstances? What protection/recourse do you have?
- Can co-workers refuse to work with you if they know or suspect you are HIV positive?
- Will disclosure of AIDS/HIV status affect your entitlement to company benefits?

Under no circumstances does HIV infection alone constitute sufficient grounds for an employer to dismiss you or to refuse to hire you. In practice, unfortunately, this kind of discrimination in the workplace does exist. Fighting against an unfair dismissal or refusal to hire you can be a daunting prospect. It can be expensive and exhausting and, in some cases, it may be hard to justify the psychological and emotional cost. However, as outlined in "Protecting Your Rights", legal opinion is against such discrimination and most cases are settled out of court.

There is no requirement for you to disclose your HIV status to anyone at work, and as long as you have no symptoms, you can postpone deciding who to tell. You can always tell someone later; you can't go back and change your mind once you have disclosed your status. If symptoms develop, the specifics of your job will play a larger role in determining what information to share and with whom. In making the decision to be more open about your condition, there are some things you may wish to keep in mind.

Larger companies and organizations usually have certain people or departments who deal with employees' health and welfare issues. Your dealings with them should, and very likely will, remain confidential. However, given the problems which can arise if they do not keep your status confidential, you may be wise not to take this on faith. Unauthorized and inappropriate disclosures, made with the best of intentions, (so that co-workers would be "sensitive and understanding") can lead to crisis situations; these can be difficult and expensive for employers, frightening and upsetting for other employees, and potentially devastating for you.

The right to confidentiality frequently exists more in theory than in practice. The actual meaning of confidentiality can also vary from person to person or situation to situation. One personnel manager may share information with the company manager and company nurse, while another, being careful to use no names, might divulge details of one individual's circumstances to another "to let him know he's not alone". Both believe that confidentiality has been maintained. It is crucial, therefore, that you have a clear mutual understanding of all expectations about confidentiality before you disclose your HIV status.

Insurance may also raise questions about confidentiality. If your company has an established group plan, there is probably little for you to worry about. However, new group plans will ask for information about HIV status and some may require HIV antibody testing. Should that happen, you would be well advised to consult with the company's health and welfare personnel who will be familiar with all the requirements of the policy and who will know if alternatives

exist. There may be circumstances under which employees are not expected to belong to the group insurance plan. Group plan options vary from company to company and you would be wise to find out the specifics of the plan before becoming involved.

In organizations that are not large enough to support human resources or personnel departments, health and welfare issues may be dealt with by the owner or manager. This can be a source of additional anxiety when you are HIV antibody positive. As a first step, you may want to talk with the company nurse or personnel officer, someone who can answer questions about company policy, and can offer sound information on which to base any decision about further disclosure. They may also be able to suggest possible alternatives and may, if you wish, assume the role of an advocate with management.

"Testing the waters" can be much easier than immediately confiding in someone who has a much more direct investment in the organization's efficiency and productivity. Confidentiality is also a potentially greater problem in this situation. Administrators are not generally required to possess the skills or training which would give them an understanding of confidentiality and the need to maintain it.

Many larger companies have policies on AIDS and HIV infection. Some, however, have decided against such policy (and the workplace education which is an essential ingredient of good policy) because they fear that its introduction would generate panic and fear. The opposite has in fact proven to be true; companies which educate their employees and introduce policies before the fact fare better when employees disclose their AIDS/HIV status. Although the responses of co-workers are sometimes unpredictable, these are also the companies in which an employee with AIDS/HIV is likely to encounter the least difficulty in remaining at, or returning to, work.

Those worksites which do not have separate policies on AIDS and HIV infection will generally include these either in their policies on other chronic disabilities, or in their policies on communicable diseases. Lumping AIDS and HIV infection with chronic disabilities does nothing to alleviate possible difficulties with co-workers but at least safeguards an individual's rights and benefits. Calling AIDS/HIV a communicable disease can prove to be disastrous as it not only threatens a PWA/HIV's right to work but also, at least by implication, may reinforce the misconceptions that co-workers hold about the transmission of HIV.

Many companies persist in the unrealistic belief that none of their employees will ever be affected by AIDS/HIV and so see no reason to plan for this eventuality. Unfortunately, there is little to be done about this ostrich-like position. Sadly, only personal experience seems to be an effective spur to change. There may be ways you can agitate for education and policy in the workplace, but often such activity provokes the kind of response it is designed to avert. Ironically, it can also cast suspicion on you as a "troublemaker" unrelated to your HIV status.

A company which has policy specific to AIDS/HIV will protect both the confidentiality and the right to work of an employee with AIDS or HIV infection. Thus, co-workers would know of your AIDS/HIV status only if you chose to reveal it. Should other employees refuse to continue

working with someone who is HIV antibody positive, they would be offered further education, and perhaps counselling. Refusal to work in a given situation must be based on a belief held in good faith that the situation constitutes a health hazard. As an employee cannot legitimately claim that this is the case after being given accurate information about HIV, continued refusal could result in disciplinary measures. This is also the practice in many unions. It is good to keep in mind, however, that exercising these rights may involve both more conflict and more exposure as someone with AIDS/HIV than you would find comfortable.

Everyone has the right to work as long as they are able to perform their jobs efficiently. This is usually acknowledged in workplace policies on AIDS and HIV infection, but organizations vary greatly in their ability to offer options that meet the changing needs and abilities of employees as they develop symptoms. Ideally, it should be possible to work shorter or more flexible hours, work at home, or transfer to another department. Larger companies are usually more able to offer these alternatives. However, many smaller businesses have had more to gain by retaining a valued employee as long as possible and have therefore been surprisingly creative in finding ways of doing so.

In a very small business, employees who develop symptoms may need to inform other staff of their changing health so that they can be prepared to redistribute the workload if necessary. This does not necessarily mean disclosing your AIDS/HIV status, but in such a small group you should be prepared for co-workers discovering or suspecting the cause of illness.

There is no way to predict how your co-workers will react, but it is likely that the main factor influencing their response will be their level of understanding of AIDS and HIV infection. Those who are familiar with the virus and its effects will be the most likely to respond well. Unfortunately, there are others who will not believe the information offered by experts, who will remain fearful of catching the virus and will refuse to work with anyone they suspect of having AIDS or HIV infection. This response comes from fear and prejudice but, unfortunately, there is no quick and easy cure for intolerance.

Other co-workers, when facing the idea that you could become ill and possibly die, may feel uncomfortable, frightened and unable to cope with the situation. They may feel inadequate and think that they "won't know what to say". As a result, you could feel as isolated as you would if they were afraid of catching the virus. When you have had good relationships with your co-workers, their discomfort with your anticipated illness can be extremely upsetting. Openly acknowledging their distress may make this problem easier to deal with. Reading material which presents a realistic picture of the range of AIDS/HIV infection and illness, may also be useful in helping them understand your situation.

The preparations you must make for dealing with your working future will vary depending on your situation. Determining who to tell and when to tell them will probably be the most difficult decision. There are a few ways, however, that you can make this task a little easier.

The more you know before you disclose your status, the more control you will probably have over what happens. Reading up on the basics, particularly the medical and psychosocial impacts

of the virus, is a good place to start. It may also be valuable to go over material pertaining specifically to AIDS/HIV in the workplace. This can be useful in helping you understand responses to AIDS and HIV infection in a wide variety of workplaces, as well as almost certainly giving you useful resource material for your employers or co-workers. While much of the written material concerns companies in the United States, with their differences in custom and law, the fundamental issues dealt with are the same.

It may also prove valuable to talk with others who have disclosed their HIV antibody positive status, or AIDS diagnosis, in a similar workplace, as well as with those who decided against disclosure. Understanding their experiences can often give you insights into your own situation.

If you ultimately decide against disclosing your AIDS/HIV status at work, you will have to decide how you will proceed if you begin to experience symptoms. Doctor's appointments, repeated bouts of illness, and visibly poor or deteriorating health will require some sort of explanation. It is also possible that employers and co-workers may be aware that there are certain infections and illnesses which seldom occur in people who do not have HIV infection. Therefore saying you have, for example, lymphadenopathy may be tantamount to saying you have HIV. It is also possible that the additional stress involved in trying to cope with fear of discovery may actually make your physical condition worse.

In the end, as long as you have no symptoms, you will probably find it quite easy to keep your condition to yourself. If your health begins to change, you will simply have to make as informed a decision as you can and cope with whatever problems arise. Make sure you know your legal rights, your company's policy on AIDS/HIV in the workplace, and watch out for any signs of prejudice from your employers or co-workers before you decide who to tell.

D. CLAIMING WHAT'S YOURS

It is most likely that you will continue working for a long period of time with little or no change in your health. However, the time may come where working every day may be simply too difficult. Should that occur, you may look at changing your work patterns - working at home, moving to part-time, or changing jobs to something less onerous - or consider quitting work altogether. If you decide to leave your job, you will need to know how to support yourself.

Group Insurance

The first possibility to consider is whether you qualify for disability insurance through a group plan at work. The details of coverage will vary from company to company, making it necessary to check the specifics with the appropriate person or department to determine if you are eligible. To get this information, you may have to disclose your HIV status, again raising questions of confidentiality. However if you are planning to leave, the idea of confirming your health status likely raises fewer issues than it would have earlier.

You may also be eligible for sick leave through your group medical insurance. If this is the case, try to arrange the beginning of disability or other income supplement coverage in such a way that the dates don't overlap. In other words, collect all your sick benefits before you begin collecting through any other plan.

Unemployment Insurance

When you initially leave work, you may be eligible for some form of Unemployment Insurance. If you are leaving with the intent of finding another job more suited to your physical needs, you can probably qualify for direct benefits. The amount you collect weekly will depend on the amount you were earning before you left your job. In order to qualify for benefits, you must have worked up to 20 weeks before applying; the actual number of weeks varies depending on the current unemployment rate in your region. To continue to collect benefits, you must be actively seeking work.

If you are leaving work because of illness and are not actively seeking another job, you may qualify for medical benefits under the Unemployment Insurance Plan. These benefits will last only for a certain number of weeks and, on the whole, will pay less than you would collect if you were job-hunting. Regulations for collecting Unemployment Insurance tend to change with the political climate. To be sure of current rules and benefits, contact your local Employment Centre. Addresses and phone numbers are listed in the blue pages of the phone book under Government of Canada.

Canada Pension Plan

A longer-term government income insurance plan exists under the Canada Pension Plan (CPP), which is funded by the contributions made to CPP on work-related earnings. In order to be eligible for these disability benefits, you must have contributed to the CPP for 2 of the last 5 years or 5 of the last 10 years, and you must be under 65 years of age. Your disability must be "severe and prolonged" and prevent you from continuing to work. AIDS/HIV may not seem like a disability *per se*, but it is classified as one under Canadian human rights legislation.

You can apply for CPP disability benefits through a Health and Welfare office. You will need documents proving your age and confirming your disability when you submit your application. You will also be asked about your reason for quitting work, medications you take, future treatment you expect, the dates of hospital stays and names of hospitals, and your physician's name. You will be asked to complete a medical release form, allowing the CPP office to obtain information on your condition from your doctor, and a form detailing information on your contributory salary and wage. It sounds confusing but Health and Welfare will give you a guide book on filling out the paper work. Office numbers for Health and Welfare Canada are listed in the blue pages of the phone book under Government of Canada.

GAIN - Basic Income Assistance

If you are unemployed and have few funds, you can receive provincial income assistance under the Guaranteed Available Income for Need (GAIN) plan. GAIN provides a cash allowance, indirect assistance, as well as preventative and rehabilitative social services. The basic monthly rate for a single adult with no dependents is currently \$550. If you are judged to have a permanent disability, you will qualify for a supplement to that income, currently \$140 per month. You may also be eligible for other supplements, such as a special diet allowance.

There are very strong limitations on your ability to apply for GAIN. For example, if you have assets exceeding \$1500 (\$500 if you are not judged to be handicapped), you are not eligible for income assistance. Housing, one car and household effects are not considered assets under the Act. Should you be eligible to apply, the amount you receive will depend on whether you are judged to be employable, unemployable or handicapped. A financial assistance worker will establish your eligibility for GAIN based on an income and asset test, which includes questions on such items as all assets, other funds, age and family size.

Medical benefits are available to unemployable people on GAIN but, ultimately, it is the worker who will decide if you are eligible on the basis of your circumstances. Medical benefits include the cost of medical plan coverage, relief from user charges, basic dental coverage, ambulance services, most prescription drugs and basic optical services. As well, you may be eligible for a diet allowance, coverage of costs for medical transport and costs of medical supplies. These benefits are decided on an individual basis and can be applied for through the local financial assistance worker. If you are receiving assistance from Social Services, you are entitled to a city recreation pass in your neighbourhood (e.g. The Aquatic Centre).

To apply for GAIN you must take the following to the worker: your social insurance card, two other pieces of identification, confirmation of shelter costs (e.g. rent receipt), confirmation of cost of utilities (e.g. bills for power, etc.), and any relevant asset information (e.g. title of house, bank book). Offices are listed in the blue pages of the phone book under Government of B.C., Ministry of Social Services and Housing. The MSSH office will also have pamphlets and other information on applying for GAIN which you will find helpful. If you are eligible, you can obtain assistance from GAIN within a very short period of time, even within 24 hours in emergency situations.

GAIN is not usually available to anyone under the age of 19 years. If you are under 19 and cannot live at home, you may obtain income assistance directly by seeing a social worker from the Ministry of Social Services and Housing, who will have to discuss maintenance from your parents. If you prefer, you could see a Family Court counsellor. A third option would be to live with a relative who can apply for maintenance on your behalf and also for income assistance through the Ministry, depending on the income of your parents. A final option is for you to be taken into care under the Ministry of Social Services and Housing, in which case you do not obtain direct access to income but are cared for in a foster home, group home, special care home or other service offered through the Ministry.

GAIN for Handicapped

This is a permanent designation and is again based on income and asset tests. You can have more assets and income than with GAIN and still be eligible for GAIN for Handicapped. It is well worth your while to apply under the handicapped category. At current rates, you are eligible for \$140 more per month, plus payment for costs incurred as a direct result of your disability. Basic medical benefits are automatically included in this designation and bus passes are available at a reduced rate. Costs for medical transportation and medical supplies may also be covered.

To qualify under GAIN for Handicapped you must be between 18 and 64 years of age, have an apparently permanent mental or physical disability, and have small, or no other, income. However, government rules on who qualifies as "handicapped" under GAIN can be difficult. Your disability need not be visible and AIDS and HIV infection have been accepted as a disability for GAIN benefits. Nonetheless, receiving this designation is not automatic. When you apply, you will have to show that because of the disability you need help or supervision with normal daily living or that you have unusual ongoing expenses for things like diet, transportation or other needs. You must also show that you cannot be trained or retrained for regular full-time work.

To apply for handicapped benefits, make an appointment with a financial assistance worker at your local social services office. This can be done at the same time you apply for basic GAIN assistance. Before you go, make a list of all the things you do in a day and problems you have doing them. Note especially where you need help from friends, neighbours, relatives or even strangers. Also write down all the extra things you have to pay for because of your condition; this can include fees for hobbies or other social and recreational activities which are part of medical treatment. Your worker will need all this information to fill out the application form.

Your doctor will also need to fill out a form saying you have an apparently permanent disability. It is a good idea to make sure your doctor will support you. Remember that if you are not supported, you have the right to get another opinion from a different doctor. Be sure your doctor understands the government definition of "handicapped" and that your doctor reports all of the medical problems you have. The booklet provided by MSSH on GAIN for Handicapped contains a specific explanation of what handicapped means under GAIN which you should give to your doctor before filling in the required form.

Once your doctor has returned the report to the Ministry's district office, your worker will check over the form and send it to Victoria. It will take four to six weeks for a special committee to make a decision. Your worker will inform you once a decision on your eligibility has been reached.

If you are turned down for handicapped benefits, you have 30 days from the time you are told of the rejection to appeal the decision. It is usually worth appealing, as many people who were turned down by the Ministry at first have appealed the decision and won. To appeal the decision, you must:

1. Tell your worker you want to appeal and get an appeal form. The worker should write in the reason why your application for GAIN for Handicapped was turned down.
2. Get help. Contact a group such as the Legal Services Society to find someone who will work with you through your appeal. There are a number of groups who can help you; there is a complete list of advocacy groups in the applying for GAIN pamphlet.
3. Complete your part of the appeal form. Your advocate will help you. You will need to state why you are appealing the decision.
4. Take the completed appeal form back to your local office within 30 days. The Ministry then has 30 days to review your case.

If the Ministry does not change their decision, you can ask for a tribunal hearing. You have seven days to send in the request. A panel of three people will hear your case. You have a right to choose one person on the panel. The Ministry picks the second, and these two then pick a third. They will listen to the whole case and decide whether or not the Ministry made the correct decision. Many handicapped appeals are won at this level, so it is worth taking this last step. If you haven't already, get the help of an advocate.

Once you have been accepted as "handicapped", you permanently retain that status for the purposes of GAIN. Receiving this designation can make a significant financial difference to you and you would be wise to pursue it if you have no other sources of income.

Taxable Goods

Under certain circumstances, the Province of B.C. will waive provincial taxes on items purchased by people with disabilities for use to compensate for their handicaps. The Consumer Taxation Branch in Victoria rules on a individual basis on the applicability of taxation regulations for these items. Office numbers for the Consumer Taxation Branch are listed under Government of British Columbia in the blue pages of the phone book.

Emergency Funds

AIDS Vancouver has an emergency assistance fund available to help out with rent, bedding, health and medical supplies. Wheelchairs, crutches, canes, shower seats and furniture can also be provided depending upon need. This money is not to be used as a monthly supplement, but is for emergencies only. No more than three requests in a six month period can be approved. In a six month period, \$1,000 is the maximum assistance you can receive.

The Vancouver PWA Society provides complementary health funds for full members of the Society. Full membership is open to anyone diagnosed HIV positive, whether or not they are experiencing symptoms. To qualify for these funds, you must receive a net income of less than

\$1,200 per month. Once you qualify, you are allowed up to \$75 per month reimbursement for health-related expenses not covered under other medical plans

E. HOUSING

When you are initially diagnosed with AIDS/HIV, you will probably find yourself evaluating all parts of your life as you try to sort out your needs for the future. This assessment may include your housing situation - where you live, who you live with, how much you pay monthly, etc. As with most other parts of your life, your housing needs will be determined by your own particular circumstances. However, you do have some housing options you should be aware of, particularly if your health or financial circumstances begin to change.

Property Tax Deferment

If you are classified as having a disability, you can have the property taxes deferred on your principal residence. To be eligible, you must have lived in B.C. for no less than one year and you must have equity in the property. The taxes are paid through a loan from the government which must be repaid when the property is sold, or when the estate of the owner is settled. Application forms are available from the Property Tax Section of the Consumer Taxation Branch, Government of B.C., which is listed in the blue pages of the phone book.

Rental Subsidy

The Vancouver PWA Society now operates a program of providing a limited number of housing subsidies for full members of the Society who fulfil certain eligibility criteria based on income and need. This program ensures that members pay no more than their GAIN housing allowance, or one-third of other disability income, for appropriate housing. For more information, contact the Vancouver PWA Society.

Co-ops

Housing co-operatives provide not-for-profit housing in which members own and control the housing they occupy. Housing charges are based on actual operating costs and are used to repay the mortgage and operating expenses of the property. Each member has a vote in the general meetings. Members volunteer to serve on committees or the Board of Directors to manage the operations of the co-op. Decisions about spending money, setting out co-op goals and community rules are made by members. Membership is limited to residents of the co-op.

Co-op units may not be bought or sold for profit and there is no landlord. Members may live in their units as long as they meet the conditions set out in their Occupancy Agreement. In

order to join a co-op, you must file an application and meet certain selection criteria. New members must purchase specified shares in the co-op; these shares are refundable at face value when a member leaves, minus any money owing to the co-op or any costs to repair damages. Special arrangements may be made to help you make this payment.

The Vancouver PWA Society is working with a number of co-ops to place PWA/HIVs in affordable housing units. If you are interested in this type of housing, you can fill out an application at the PWA office. Co-ops usually have a waiting list of people wishing to join. It is therefore important to fill in an application as soon as possible. For more information, contact the specific co-op you are interested in, or contact the PWA Society. You can also obtain further general information from the Co-operative Housing Federation of B.C., 4676 Main Street, Vancouver, B.C. V5V 3R7, 879-5111.

YWCA Housing Registry

The YWCA Housing Registry is a free service sponsored by the YWCA, and both municipal and federal governments. The service provides information and referrals to tenants and provides free listings for landlords. The Registry is active in helping people with AIDS and HIV infection to find affordable housing. They will also assist with information about income assistance programs and groups. For more information, contact the YWCA Housing Registry at 501 East Broadway, Vancouver B.C. V5T 1X4, 873-1313.

McLaren Housing Society

The McLaren Housing Society operates a group home, McLaren House, and a small apartment residence, Helmcken House, for people with AIDS and HIV infection who need affordable housing. McLaren House operates cooperatively and Helmcken House is run much like any other apartment building. Both are managed by a Housing Coordinator.

If you are interested in living at McLaren House or Helmcken House, you must make an application which will be reviewed by the Board. Residents are chosen from current applications when a vacancy occurs and a waiting list is maintained. For further information, contact the McLaren Housing Society at 732-3802. You can also obtain information and file an application through the Vancouver PWA Society.

Other Options

Despite the services outlined above, it is difficult for PWA/HIVs to find affordable housing, particularly in Vancouver. As rents continue to skyrocket throughout the Lower Mainland and in the Victoria area, many people face difficulties in finding suitable accommodation. This problem can be even more complicated if you have AIDS/HIV and your medical condition limits

the kind of housing available to you. If you need to have a roommate, you may find it difficult living with someone who does not understand your condition and the demands you face.

You will find that an informal network exists through the Vancouver PWA Society. Available rental space is frequently posted on the bulletin board in the lounge, as are listings of people looking for roommates. Just talking with other PWA/HIVs will frequently give you good hints on where to find what you want. Furniture, dishes, clothing, etc. are also available through the PWA Society on occasion, usually on a first come, first served basis. If you particularly need something, you can check with the office, or check the lounge.

CHAPTER FOUR: LEGAL ISSUES

A. GETTING YOUR AFFAIRS IN ORDER

A diagnosis of AIDS or HIV infection does not mean you will immediately die. Nonetheless, it can mean that you will deal with serious illness within the next few years, and that possibility raises practical, legal issues you should consider. Making these decisions can be difficult, but it is wise not to put them off until the last minute. It is better to think about them, talk about them, and make arrangements while you easily can.

You should give some thought to sorting out your personal papers, labelling them, and clearly marking anything that would not be obvious if you could not explain what it was. Listing all your papers in one place will help you to remember everything and, if necessary, help someone else sort things out.

In the meantime, you can take practical steps to protect your medical rights, your business affairs, and to make the final arrangements you would like.

B. PROTECTING YOUR MEDICAL RIGHTS

Medical care, as long as you are feeling well or are experiencing only a few symptoms, will ideally be a matter of open communication between you and your doctor. However, the time may come when you will be too ill to express an opinion on your medical treatment. Unless you take legal steps to make your wishes clear, the type of treatment you receive will probably be decided by your medical team, possibly in consultation with your family.

There are two legal documents you can prepare now which will help you maintain control over the kind of medical care you receive. These are a Living Will and an Enduring Power of Attorney for Health Care.

Living Will

A Living Will is a document that expresses your preference about medical treatment when you are critically ill.

Should you be in hospital with serious illness, the issue of whether you want extraordinary or "heroic" measures taken to prolong your life may come up. Normally, if you are too ill to make these kinds of decisions, your next of kin will be asked to decide for you. The law assumes you want blood relatives making judgements for you if you cannot make them yourself. This may or may not be what you actually want.

Most Living Wills amount to the choice to refuse life-sustaining medical treatment in the event of terminal illness or injury. However, in the document you can give specific instructions

beyond that. For example, you can say you will or will not go on a respirator, depending on particular circumstances. The possibilities involved are often complex. Rather than simply refusing life-sustaining treatment, you would be wise to talk the whole thing over with your doctor or someone else who is knowledgeable. Even diseases such as Pneumocystis Carinii pneumonia (PCP) are no longer necessarily fatal and "heroic" measures have extended lives for a number of years. A Living Will is a valuable document, but it is equally valuable to be certain of exactly what you are choosing.

In British Columbia there is no legal requirement for a doctor, or anyone else, to carry out the terms of a Living Will. However, it does indicate your wishes to the people looking after you. Talking the issues over with your doctor when you write your Living Will can ensure that you both agree on the types of treatment you'll receive. If your doctor does not agree with your wishes, you can always find another doctor.

You must be at least 19 years old and of "sound mind" to make a Living Will. You can ask for a lawyer, a social worker or a doctor help you write the document. Or you can write it yourself. You do not need a lawyer and you do not need the document notarized. All a Living Will requires to be legal are two witnesses to your signature. The witnesses cannot be related to you, cannot include the people who are providing you with medical care, and cannot be anyone entitled to part of your estate, or with a claim against your estate. Make sure that your doctor, your next of kin, and the people closest to you have a copy of your Living Will. If you are going into hospital, give a copy to a caregiver on the ward for inclusion in your chart.

Examples of Living Wills are available at the Vancouver PWA Society, AIDS Vancouver, or from your social worker or hospital staff.

Enduring Power of Attorney for Health Care

If you wish, you can appoint a particular person to make decisions for you about your medical treatment when you are too ill to make them yourself. This legal relationship is called an Enduring Power of Attorney for Health Care and can include terms like giving this person (called your attorney) full access to your medical and hospital records, and the power to make decisions about who can visit you.

An Enduring Power of Attorney for Health Care is like a Living Will, in that there is no legal requirement for a doctor, or anyone else, to carry out its terms. However, it does clearly indicate to doctors and hospital staff who you would like them to consult on your care. This is especially important if the person you would like them to confer with is not your next of kin. Again, it is wise to talk your wishes over with your doctor when you actually write the document to make sure your wishes are understood and will be respected.

An Enduring Power of Attorney for Health Care can also be drawn up without a lawyer and simply needs two witnesses to your signature to be legal. The witnesses cannot be your health care providers nor include anyone with claim to your estate. You should give copies to those

closest to you, your next of kin, and include them in your medical files. Examples of Enduring Power of Attorney for Health Care documents are available through the Vancouver PWA Society or AIDS Vancouver.

C. PROTECTING YOUR BUSINESS AFFAIRS

Protecting your business affairs can be a major concern if you become ill for any length of time. Simply spending time in hospital can make it difficult for you to manage your concerns. There are certain illnesses associated with AIDS and HIV infection which can cause mental incapacity and certain drugs or combinations of drugs which can cause mental confusion. Losing control is a frightening possibility, but you should give thought to who you would want to handle your interests under those circumstances. Planning for a possibility does not mean it will happen.

Power of Attorney

The main way to give someone else legal authority to act for you is by giving them your "Power of Attorney". This power is used mainly for money and property matters, although it can be used to make decisions for you in other areas. The person you give this authority to is then called your "attorney". Despite the title, this person does not have to be a lawyer; you can give a Power of Attorney to any adult you trust. It's a good idea to name a second person to act as an alternate attorney, in case the first attorney becomes unable to act.

The kind of control your attorney has over your affairs will depend entirely on how much power you give them. A general Power of Attorney means your attorney will act for you in financial dealings like banking, signing contracts, buying or selling real estate, or buying consumer goods. You can also give a Power of Attorney for limited purposes, such as banking and bill paying, or you can add other responsibilities, such as taking care of a pet, to a general Power of Attorney.

When you give a general Power of Attorney to someone else, you do not lose control over your affairs. From that time on, you share authority with your attorney, but you only lose the right to make your own decisions should you become mentally incompetent. You also have the alternative of giving someone your power of attorney only in the event that something happens to you. However, if you do not state in the Power of Attorney that it comes into effect at a later date, your attorney will have control as soon as you sign the document. You can also include an accounting process in the Power of Attorney, which means that your attorney must report to you about your money and assets on a regular basis.

As long as you are mentally competent, you can cancel the Power of Attorney at any time. If it has never been used, you can simply destroy it. Once it has been used, you cancel the authority by signing a statement saying you "revoke" the Power of Attorney. You should send

a copy of this statement to the person who was acting as your attorney, to the Land Titles Office if you own real estate, and to anyone else, such as your bank manager, who needs to be notified.

To protect you from any abuse of power by your attorney, the Power of Attorney ceases to be effective if you become mentally incapable of handling your affairs. If you wish your attorney to continue to act for you under those circumstances, you must add this authority to the written Power of Attorney. This extended appointment is called an Enduring Power of Attorney. If you don't include this statement and are later declared mentally incapable, your financial affairs will be handled by the Public Trustee or a "committee of the estate". If you become bankrupt or die, the Power of Attorney ceases automatically.

A Power of Attorney must be in writing and notarized. Lawyers and notaries charge a reasonable fee for preparing this document, although if you wish, you can buy a form called a "General Power of Attorney, Short Form" from a stationary store. You should be aware that many banks will not honour a General Power of Attorney form and that you will also have to complete a separate Power of Attorney form through your bank.

A Power of Attorney lasts for only three years unless it is an Enduring Power of Attorney. An Enduring Power of Attorney is ongoing and allows your attorney to handle your affairs indefinitely. An Enduring Power of Attorney will only be terminated if it is revoked, or through bankruptcy, death or the appointment of a Committee.

Committeeship

If you become mentally incapable of managing your affairs and if you have not previously granted an Enduring Power of Attorney, the Court will appoint a Committee to manage them for you. A Committee may be one or more persons, a trust company or the Public Trustee. The Committee is appointed by a British Columbia Supreme Court judge after two doctors certify that you are unable to look after your affairs and/or yourself. You may oppose the application either in person or by having a lawyer appear on your behalf.

As long as you are mentally competent, you may nominate whoever you would want to be your Committee should that become necessary. You can do this by completing a document called a Nomination of Committee which must be signed in the presence of two witnesses. The Court will appoint your nominee despite objections by relatives unless the nominee's mental health or honesty are in question. If you have not nominated anyone, the Court will appoint either a relative or the Public Trustee as your Committee.

When the Public Trustee acts as your Committee it is usually only in relation to your affairs - your banking, entering contracts on your behalf, selling property. Decisions relating to your care and treatment are usually left to your relatives or to the hospital staff if there are no relatives. Your Committee is required to keep careful records of your financial affairs and report to the Public Trustee every two years. This is intended to protect you against an

unscrupulous Committee. Your Committee is entitled to claim fees from your estate for their work in managing your affairs.

What Documents Do You Really Need?

Sorting out exactly what you need and what you don't can be confusing. When it comes to business affairs, you should consider having a Power of Attorney in place for times when you can't manage your affairs by yourself. Because there is a chance that illness can cause you to become mentally incompetent, you would be wise to consider an Enduring Power of Attorney which will keep the same person in control under those circumstances.

An Enduring Power of Attorney can be terminated by the Court if, for example, your family asks that a Committee be appointed instead. For this reason, you should consider drawing up a Nomination of Committee, stating who you want in that position. While the Court does not have to agree with your wishes, they probably will. It is also quite possible that no one will ask that a Committee be appointed if you have an Enduring Power of Attorney in place.

An Enduring Power of Attorney can give your attorney the same control over your medical treatment that is covered under an Enduring Power of Attorney for Health Care. However, if your Enduring Power of Attorney is challenged in Court and replaced by a Committee, your attorney's control over your medical treatment also ends. By having a Living Will and an Enduring Power of Attorney for Health Care, you will have made your wishes clear and they will probably be respected.

D. FINAL ARRANGEMENTS

Death is a fact of life. Being diagnosed with AIDS or HIV infection is not an immediate death sentence, but it can raise issues you may not have considered until now. There are steps you can take to maintain control of your affairs after you die.

Funerals

No one likes funerals. But you probably have some ideas on how you want yours handled. There is no legal way to guarantee your wishes will be respected - that will be up to your next of kin - but you can make the arrangements you want with a funeral home, pay ahead for services, and certainly make your wishes known. Setting up arrangements when you're clear-headed and not under emotional pressure will make the whole situation easier for everyone.

You can obtain specific information on funerals through the Vancouver PWA Society, AIDS Vancouver and AIDS Vancouver Island. Other PWAs have also dealt with these same issues and they may have some suggestions. Whatever you do, be sure to shop around before you sign

anything. Funerals don't need to be expensive, but they certainly can be. Also talk over what you want with your family and with those closest to you. They will be much more likely to respect your wishes if they know what your wishes are.

Another eventuality you should consider is that, following your death, the hospital may request permission from your loved ones to do an autopsy for the purpose of "medical science". You and your loved ones may have different opinions on this process, and you would be wise to make your wishes known to them, to your physician, and to whoever you have made responsible for your medical care. In this, as in other matters, your wishes are likely to be respected if they are known.

Leaving a Will

A will states who you want to leave your assets and property to after you die. If you do not leave a will, your estate will automatically go to your nearest relatives. If no relatives are known or can be found, your estate will go to the government.

If you have no will to say otherwise, any property you own with someone else (including joint bank accounts) will go directly to the other owner, although that process may be delayed until your estate is probated.

When you write a will, you should state exactly what you want to happen to everything you own. This should include a general statement on where anything that you haven't specifically listed should go. In writing your will, you should also name someone - called the executor - who will be responsible for taking care of your estate. This should be someone you can trust to carry out your wishes. As a safeguard, you can appoint two executors in case one is unable to act. If you do not name an executor, the Court will appoint someone (probably a relative) to administer your estate.

A Will is only effective for property that you own or have an interest in. If you have insurance policies, RRSPs, pensions and other similar benefits, check to see if you can name a particular person who would receive these benefits when you die. If you do not want to name a specific person, you can name your estate, and then the benefits will be dealt with along with the rest of your property, according to your will. You should not mention in your will any jointly owned property that already has a legal right of survivorship in place.

You can hire a lawyer or notary to write your will, or you can do it yourself. If your estate is large and/or if you have large debts, a legal spouse, legal dependents, a community property agreement - or if the estate may be in dispute for any reason - you should have a lawyer write your will. A well-written will in the safe-keeping of your lawyer makes it easier to establish that the will is, indeed, your last will, and is valid.

If what you have and who you want to leave it to is a relatively straightforward matter, and you have no large debts, you can write your own will, or fill in a standard will form that you buy

at a stationary store. There are a number of self-help guides on will preparation which you can use as well. However, before you decide to go ahead without a lawyer, make sure there is not going to be any dispute over who will benefit from your will, or whether you were mentally capable of writing it.

For a will to be legal, you need two adult witnesses to your signature, and they both must be present at the same time to witness each other's signatures. A witness cannot be a beneficiary in the will or the gift left to that witness will be void. Your executor, if not also a beneficiary, can be a witness.

If you make any major changes in your circumstances, you should change your will. You can make minor changes through a codicil, which must be signed and witnessed in the same way as a will. Do not erase or alter the will itself. If you want to make major changes, make a new will.

Bank and Saving Accounts

After a death, personal assets, including bank accounts, are "frozen". It is then the duty of the administrator of the estate (if there is no will) or the executor (if there is a will) to go over the assets and liabilities of the deceased and fulfil the terms of the will. Sorting all this out will take time, especially if there is no will.

If you and your partner have a joint account, when either of you dies that account will be frozen as if it was only in the name of the deceased. That could leave the survivor without funds until the will is sorted out. Rather than have that happen, you can rearrange your assets, particularly the cash in bank accounts. Before going ahead, be sure to check any changes you want to make with your lawyer or accountant.

Inheritance Tax

Depending on the value of your estate and who is inheriting, your heirs may end up having to pay inheritance tax. Tax rules depend on a number of factors, but the tax rate can be significant. Where your estate is worth a large amount, it may be worth considering ways of avoiding tax liabilities. For more information, consult an accountant or a tax consultant.

CHAPTER FIVE: UNDERSTANDING YOUR MEDICAL CONDITION

A. HOW DO YOU FEEL?

How do you feel? Before you became infected with HIV, that was a simple question. Now every time you have an ache, pain, rash or any other symptom you can't immediately explain, you're likely to suspect the worst. Even being overtired can feel like the beginning of prolonged illness.

When your physical condition changes, it is impossible to tell immediately what has caused the change. The symptoms related to HIV infection (sometimes referred to as AIDS Related Complex or ARC) are very much like the symptoms of a number of other infections. These symptoms may include:

- unexplained, persistent fatigue;
- unexplained fever or shaking chills;
- persistent drenching night sweats;
- unexplained weight loss;
- continually swollen glands (enlarged lymph nodes, usually in the neck, armpits, or groin);
- persistent white spots or unusual blemishes in the mouth;
- persistent diarrhea for no known reason;
- unusual bruising or bleeding.

Many of the same manifestations can come from something as simple as the flu, although the symptoms of HIV infection tend to be longer lasting, more severe or recurrent. The only way to know for sure what you are dealing with is to see your doctor.

Being diagnosed with HIV infection or ARC still does not mean you will immediately develop AIDS. It is not possible to tell when you will become ill and how ill you will be at any given time. How you feel can vary from day to day. Some people become ill enough to qualify for disability; others suffer minor symptoms for long periods of time and continue with their normal activities.

Again, it is important to check with your doctor as most symptoms can be treated with existing medications. Your doctor will be able to spot if your symptoms arise from a reaction to your drugs, rather than from an infection. It is also valuable to learn as much as you can about your condition to ensure you maintain a knowledgeable partnership with your doctor on decisions regarding your health.

B. COMMON ILLNESSES ASSOCIATED WITH AIDS

The Human Immunodeficiency Virus (HIV) creates disease by taking over the command structure of T-cells which are part of the body's immune system, the system that usually clears

infectious agents (bacteria, viruses, fungi, protozoa) and cancer cells from our bodies. The virus then commands the T-cell to make more virus, eventually killing the cell itself, releasing more virus into the blood stream to infect more helper T-cells. Eventually the immune system loses a critical number of these vital cells and becomes unable to combat infections.

A healthy immune system is normally very successful at combating potentially infectious agents. Many of these agents can live harmlessly on the surface of our mouths or lungs, but create clinical symptoms when the immune defence is too weak to stop them from invading the body. Fortunately, infection with HIV by itself does not make the body more susceptible to all diseases. For example, people with HIV do not normally have more difficulty fighting off cold or flu, although dealing with these can cause extra stress to the body. Even in these cases, your body may have a harder time dealing with these invaders as your immune system becomes progressively weaker.

AIDS is generally diagnosed when immune deficiency reaches a point that certain specific opportunistic infections or cancers occur. However, people's experiences with the virus vary widely and it is impossible to predict which infection a person will develop, how severe symptoms will be, or how each case will respond to treatment. Nevertheless, all opportunistic infections and cancers associated with AIDS and HIV infection can be serious and should be treated immediately. When in doubt, check with a doctor.

The following are common conditions associated with AIDS and HIV immune suppression:

ANEMIA:

A condition in which the hemoglobin in the blood, the part of the blood which carries oxygen, is reduced. The main symptoms are excessive tiredness, breathlessness on exertion, pallor, and poor resistance to infection. Anemia is usually a symptom of another infection or is caused by the body's reaction to a particular treatment. For example, anemia can be a symptom of bone marrow failure as a result of infection in immuno-deficient people. It can also arise as a reaction to drug or radiation treatments. It is a treatable condition and should always be considered when you feel excessively tired or generally unwell. The treatment for anemia depends on the cause.

BRONCHITIS:

This condition is common to the general population in winter, but because the body's defences are lower with AIDS/HIV, it is seen more frequently when the immune system is compromised. Bronchitis is an inflammation of the bronchial tubes in which the major airways become infected, and the bronchial mucous glands become enlarged. This inflammation causes wheezing and coughing up of the excess mucous.

To ensure that pneumonia does not develop, early consultation with a doctor is recommended to obtain appropriate antibiotics.

CANDIDA INFECTIONS (CANDIDIASIS):

The fungus *Candida albicans* is one of the normal organisms found in the mouth, gastrointestinal tract, vagina and skin of healthy individuals. It produces infection only when the immune system is suppressed for any reason (including diabetes, immunosuppressive drugs and aging). The infection it produces is yeast-like and affects membranes, the skin and internal organs.

The most common site of infection is the mouth. The oral candida infection is called "thrush" and appears as white or cream-coloured patches on the tongue, lips, throat and inside of the mouth. It can be partially scraped off, but recurs. It may cause swelling, redness, painful or burning sensations, a peculiar taste in the mouth, and bad breath. If not treated it can look like cottage cheese lumps. Other common sites of infection are the nailbeds, umbilicus, around the anus, and inside the throat. Very occasionally, candida can affect the heart and the lining around the brain and spinal cord.

If you experience Candida symptoms, consult your doctor for the most appropriate treatment. To date, Diflucan (fluconazole) is the most effective drug.

CENTRAL NERVOUS SYSTEM (CNS) DISEASE/DEMENTIA:

AIDS/HIV-induced CNS disease (sometimes referred to as cognitive impairment or dementia) is a chronic or persistent disorder of the mental processes due to the effect of AIDS/HIV infection on the brain and central nervous system. It is marked by memory disorders, changes in personality, deterioration in personal care, impaired reasoning ability, and disorientation. Suspicion of CNS should be checked with the doctor as the same symptoms can arise from opportunistic infections or from reactions to drugs or combinations of drugs.

CRYPTOCOCCAL INFECTIONS:

Cryptococcus is a fungus which exists commonly in the environment and grows in pigeon droppings. Humans acquire it by inhaling dust contaminated by the fungus. Cryptococcal infections have occurred in otherwise healthy people, but are more likely to occur in people with compromised immune systems. The most common site of infection is in the meninges (membrane covering the brain and spinal cord) of the central nervous system; this infection creates symptoms and is diagnosed as cryptococcal meningitis. The fungus can also be found in the lungs, blood, kidneys, bone marrow, liver, lymph nodes and skin abscesses.

The onset of cryptococcal meningitis may be gradual or sudden, and the symptoms can be varied and vague. Symptoms can include increasingly severe headaches, blurred or double vision,

dizziness, confusion, nausea and vomiting, speech difficulties, ringing in the ears, difficulty walking, memory changes, inappropriate behaviour, irritability, psychotic symptoms, seizures, and fever. If untreated, the infection can progress to coma and death.

A diagnosis is made through culturing a sample of spinal fluid removed through a procedure called a spinal tap (or lumbar puncture). Treatment is through prolonged drug therapy. The drugs used are toxic, produce side effects, and need close medical supervision. A less toxic treatment is Diflucan.

CRYPTOSPORIDIUM

This is a protozoan, normally found in farm animals, which causes diarrhea. In people with healthy immune systems, the diarrhea usually goes away without treatment in two weeks. In people with suppressed immune systems, the diarrhea can be long lasting and very debilitating.

Cryptosporidium enters the body through the mouth, is swallowed and establishes infection in the bowel. It is transmitted by direct or indirect contact with feces from infected animals or persons. Direct contact may occur during oral-anal sex practices; indirect contact occurs through ingestion of food or water that have been in contact with objects contaminated by feces.

Generally, medical treatment is directed toward replacing the fluids lost through diarrhea and decreasing the symptoms of abdominal cramping, nausea, vomiting and appetite loss that often accompany the diarrhea. It is not uncommon for people with profuse diarrhea to require hospitalization for intravenous fluid replacement. Antidiarrheal drugs may help.

CYTOMEGALOVIRUS (CMV) & CMV RETINITIS

This virus is related to the herpes family. CMV infections may occur without symptoms or result in mild flu-like symptoms of aching, fever, mild sore throat, weakness, and enlarged lymph nodes. Severe CMV infections can result in hepatitis, mononucleosis, or pneumonia even in people who do not have compromised immune systems.

In people with AIDS/HIV, the virus can infect major organs and result in pneumonia, colitis (bowel infection), encephalitis (brain infection) and/or retinitis (infection of the retina of the eye). CMV retinitis is particularly common; it usually appears as blurred vision, but can sometimes lead to blindness. CMV can also appear with other opportunistic infections. For example, pneumonia can be caused by infection from CMV and pneumocystis at the same time.

The most used treatments in Canada for CMV retinitis are gancyclovir and foscarnet. Both are obtainable through your doctor.

EPSTEIN-BARR VIRUS (EBV):

This is a herpes group virus which causes one of two kinds of mononucleosis (the other is caused by CMV). The virus lodges in the nose and throat and is transmitted by kissing. EBV lies dormant in the lymph glands and has been associated with Burkitt's lymphoma, a cancer of the lymph glands. This is one of the clearest links to date between virus and cancer.

HAIRY LEUCOPLAKIA:

Sometimes mistaken for thrush, hairy leucoplakia appears as thickened white patches on mucous membranes, such as the mouth lining, particularly on the sides of the tongue, due to an overgrowth of the tissues. It is usually thicker than thrush and cannot be scraped off. It is called "hairy" because of its appearance, which is like wet cotton or velvet. This condition is strongly associated with AIDS/HIV immune suppression.

HERPES:**Herpes Simplex:**

This virus results in cold sores or fever blisters on the mouth or around the eyes. Like all herpes viruses, this may lie dormant for months or years in nerve or lymph tissue and flare up again under stress, trauma, infection or immunosuppression.

Another form of herpes, known as genital herpes, results in ulcers around the anus or genitals. It is sexually transmitted and is a very common infection in people with AIDS/HIV immune suppression.

You may acquire either type of herpes in the genital area or in the mouth.

Herpes Varicella-Zoster Virus:

The varicella virus causes chicken pox in children and may reappear in adulthood as herpes zoster. Herpes zoster, also called shingles, are small very painful blisters on the skin. They appear most commonly as a rash around the torso following the lines of the nerves, with clear demarcation from unaffected skin. They can also occur elsewhere on the body. After the rash settles, a long period with an aching sensation may follow.

In people with AIDS/HIV, herpes infections may be especially severe and/or prolonged. Herpes infections may become disseminated and affect large areas of the skin and major organs such as the lungs, brain and gastrointestinal tract.

Treatment consists of acyclovir in pill form or as an ointment applied to skin sores. If the outbreak is severe, intravenous acyclovir is given. Acyclovir is well tolerated and has few side effects. Many doctors treat patients with acyclovir, sometimes in combination with an anti-viral such as AZT, on a long term basis as there is evidence that the herpes virus also activates HIV.

KAPOSI'S SARCOMA (KS):

Kaposi's Sarcoma (KS), one of the major conditions associated with a diagnosis of AIDS, is a cancer of the connective tissue that supports blood vessels. Although this cancer was first identified over a century ago, it was extremely rare, appearing either in elderly men of Jewish or Mediterranean origin or in certain African tribes. It has now reached almost epidemic proportions among people with AIDS, although it is more common among gay men than among other groups affected by AIDS.

KS most often occurs as lesions on the skin, but it can occur in the nose, eyelids, mouth, rectum or anywhere internally, especially in the lymph nodes. On the skin it shows as purplish red spots about the size of a dime to the size of a silver dollar. The spots tend to grow in size as they get older. The spots usually do not hurt or itch, although either sensation may occur. KS, like other cancers, can also cause mild fever, weight loss, and a sense of fatigue.

Treatment until recently has been radiation and/or chemotherapy. Alpha interferon has also shown promise as a KS treatment. It has been approved for that purpose in the USA and is available by prescription in Canada. Pentosan is a new drug for KS which appears to have fewer side effects than alpha interferon and is less expensive. This drug will soon be available through the Emergency Drug Release Program.

LYMPHADENOPATHY:

Otherwise known as swollen lymph nodes. Any time an infection occurs, some lymph nodes swell up, usually the ones nearest the infection. In the presence of HIV, the nodes may remain swollen for extended periods of time; this condition is referred to as Persistent Lymphadenopathy Syndrome or PLS. The swollen lymph nodes may be sore or visible externally, but not always. Swollen lymph nodes should be checked with the doctor if they persist as they may be a sign of lymphoma or other opportunistic infections. PLS usually occurs early in HIV infection. However, if it occurs later, it is not PLS, but is indicative of something more serious.

LYMPHOMA:

Lymphoma refers to any malignant tumour of the lymph nodes, excluding Hodgkin's disease. (Hodgkin's disease refers to a specific malignant disease of the lymphatic system; many symptoms of Hodgkin's are the same as symptoms of lymphoma.) Lymphoma is usually marked by multiple enlarged lymph nodes, often with symptoms like weight loss, fever and sweating.

Treatment with drugs is the norm. If the disease is localized, it may be treated by radiotherapy followed by drugs.

MYCOBACTERIUM AVIUM INTRACELLURARE (MAI):

MAI is from the same family of bacteria as tuberculosis (TB) and leprosy. The disease is extremely rare in the general population, but fairly common when the immune system is suppressed. MAI infects the bloodstream, internal organs, bone marrow, and lymph nodes, but rarely the lungs. The most common symptom is prolonged, severe wasting. Other symptoms may include fever, fatigue, swollen glands, night sweats and diarrhea.

Treatment has been tried with various combinations of several drugs used against TB, with varying success. Such treatments can be difficult as the drug combinations used can have toxic side effects. The most promising current treatment appears to be a drug called clarithromycin which is an erythromycin-related antibiotic. Clarithromycin is available in Canada upon request by your doctor under the Emergency Drug Release Program. As of 1993, we are using rifabutin in combination with another agent as a prophylaxis for MAI.

PNEUMOCYSTIS CARINII PNEUMONIA (PCP):

PCP is a generally rare lung infection which is a distinct threat to someone with immune deficiency. It is considered one of the major conditions associated with a diagnosis of AIDS. It appears to be caused by an organism which is air-borne and common, but no danger unless the immune system is depressed.

The protozoa creates disease by multiplying in the air sacs (alveoli), causing a response as the body attempts to fight it off by having white cells, fluids, etc. enter the air sacs. These sacs, therefore, fill with fluid and debris and the usual oxygen exchange is reduced. People become short of breath, develop a deep hacking cough, and have high fevers and sweating.

PCP can be treated by taking I.V. or oral Pentamidine or Septra. There are also treatments which prevent PCP from occurring and are taken as a prophylaxis or preventative. The three most common are Dapsone which is the easiest to take, Bactrim or Septra, or Pentamidine taken in aerosol form to coat the lungs. Recent studies have also begun to show that steroids are useful as a treatment for moderate to severe PCP; it is less certain whether they are helpful in treating mild PCP.

TOXOPLASMOSIS:

Toxoplasmosis is a protozoan which can cause birth defects in children born to mothers infected during pregnancy and is known to cause infection in the brain, lungs or heart of people with compromised immune systems. This protozoan is quite common and exists in an inactive state which does not cause disease in many people; however, the organism may activate when the immune system is depressed. Toxoplasmosis may be acquired through eating raw or uncooked meat containing this organism. It is also found in the feces of infected cats, although the feces do not become infectious until one to four days after being excreted.

Toxoplasmosis in people with suppressed immune systems most often results in brain infections and is a serious and rapidly progressing disease. Initial symptoms are seizures, confusion, dizziness, headaches, fever and generalized weakness. Standard blood tests are not helpful in diagnosing the disease as they only show exposure at some time to the protozoan, not whether the infection is active. A CAT scan (a sophisticated form of x-ray) can be helpful in pinpointing the size and area of brain abscesses, but a brain biopsy is necessary to confirm the diagnosis.

Treatment for toxoplasmosis is drug therapy. During therapy, the patient will dramatically improve, but the therapy will not destroy all infection and a complete cure is not likely. Therefore, people with AIDS usually continue drug therapy for toxoplasmosis indefinitely.

TUBERCULOSIS (TB)

This organism can cause disease even when T-helper cell counts are relatively high. Symptoms of active disease are swollen lymph glands, fever, night sweats, weight loss and the spitting up of blood.

Tuberculosis is curable by treatment with antibiotics.

C. DRUG TREATMENTS

There is probably no area that changes more quickly or is surrounded by more controversy than that of drug treatments for AIDS and HIV infection and related illnesses. Research is proceeding on many different fronts and a substantial number of drugs are now in various stages of testing. There is not yet a "cure" for AIDS. That is to say, there is no drug treatment which effectively eliminates the virus. However, there are drug treatments which slow the spread of the virus and drug treatments which effectively deal with opportunistic infections arising due to immune suppression.

Determining which drugs to use when dealing with AIDS and HIV infection will require consultation with your doctor and possibly some research on your part. New drugs are coming on the market all the time. However, certain drugs are common in the treatment of AIDS/HIV

and the related infections. These drugs can be categorized as (1) Antiretrovirals, (2) Immune Stimulators, (3) Infection Fighters, (4) Anti-cancer Drugs. Although a procedure, rather than a drug, an experimental treatment called Passive Immunotherapy is also beginning to show promise.

ANTIRETROVIRALS:

Antiretrovirals are drugs which prevent or inhibit HIV from infecting the body's cells, from reproducing, or from going on to infect other cells. At present, AZT and ddI are used in Canada for treatment of HIV infection. A number of other drugs, including ddC, and Peptide T are looking promising. The information on current and new antiretrovirals is constantly changing. For more complete information or updates on drugs, contact the Treatment Information Project at the Vancouver PWA Society.

AZT:

AZT was, until recently, the only antiretroviral drug against HIV on the market. The drug is clinically called Zidovudine, but has been nicknamed AZT after its components. It is manufactured by Burroughs Wellcome under the brand name RETROVIR.

The use of AZT has been controversial. It was approved for treatment of HIV infection by the U.S. Food and Drug Administration (FDA) in March of 1987 and is now fully available in Canada. The early controversy on the drug arose from the speed at which it was approved for use. While most drug approval in the U.S. takes seven to nine years after human testing begins, AZT approval took approximately 1 1/2 years. Drug approval was "fast-tracked" as early results indicated that those taking the drug were staying healthier than those who were not taking it.

There is still a lingering aura of controversy surrounding AZT, and studies on the drug seem to add to the confusion. AZT cannot kill HIV, but certain evidence seems to indicate that it slows the progress of the disease. Other studies seem to show that AZT produces greater benefit with fewer side effects when the drug therapy begins prior to the onset of any major illness. Certainly over the years, the recommended dosage has decreased dramatically and it seems evident that a lower daily dosage of AZT is more beneficial in the long run than is a higher dosage. Some recent studies, however, have suggested that AZT may have little effect in prolonging life expectancy, and that the damaging side effects may outweigh the potential benefits of the drug.

AZT is a very potent drug and there are people who cannot take it. This seems to be particularly true in cases where the person has previously had a serious illness such as hepatitis. There is also some evidence that the virus becomes immune to AZT after an average of 18 months of treatment.

Particularly when given in higher doses, AZT can produce serious side effects. It is important to contact your doctor if you experience any symptoms of drug reaction as these can often be controlled through dosage adjustment. The most common side effects to AZT are:

1. Anemia:

AZT suppresses the bone marrow, which is where our blood cells are manufactured. This can cause anemia, a condition in which the bone marrow does not make enough red blood cells or enough hemoglobin to get adequate oxygen to body tissues. Signs of anemia include extreme tiredness, shortness of breath, dizziness, confusion, and headache or pounding sensation in the head. Anemia caused by AZT can be alleviated in several ways:

- a) decreasing the dosage of the AZT;
- b) temporarily stopping the treatment;
- c) receiving regular blood transfusions;
- d) stopping AZT entirely.

2. Low White Cell Counts:

White blood cells help fight infection and are also made by the bone marrow. A shortage of them can cause added problems with infection. This decrease in white blood cells may mean you will have to decrease or stop the AZT to prevent any added danger of infection.

3. Liver Damage:

There is some indication that AZT can cause liver damage, particularly in people whose livers have been previously weakened by infection or excessive alcohol use. Earlier exposure to hepatitis, for example, may make this side effect more likely. Liver involvement usually means decreasing the dosage or stopping AZT entirely.

4. Nausea:

Occasionally people taking AZT experience nausea. With some, it goes away after a few weeks; some just get used to it; and a few have problems no matter how long they take the drug. The biggest problem with nausea is that it can decrease the appetite and lead to weight loss. The nausea can often be countered by taking the AZT along with food, or by drinking large amounts of water. Eating smaller, more frequent meals can also help.

5. Neuropathy:

In some cases, AZT can lead to symptoms of neuropathy causing weakness or numbness of peripheral nerves. This will usually first appear as a lack of sensation or numbness in fingers or toes, gradually spreading to other nerve endings. As this symptom can be caused by HIV infection as well as by reaction to AZT, you should always consult your doctor to ensure proper treatment. AZT-induced neuropathy usually eases when the dosage is reduced, but may necessitate stopping the drug.

In most cases, the higher the dosage of AZT, the worse the side effects seem to be. Recent studies show that a lower dosage can produce the same or better results than the high dosages first used. Studies are also showing that AZT is effective when prescribed at an earlier stage of HIV infection. Canadian guidelines have now made AZT available for anyone testing positive for HIV, whether or not they are displaying symptoms of disease. The normal range of T4 cell counts is between 410 and 1300.

The actual dosage of AZT you take will be determined by you and your doctor. Your capsules should be protected from extreme temperatures to maintain their potency. The manufacturer recommends keeping them around 20° Celsius. This can be difficult to do, but there are certain hints that help:

- 1) Do not carry them in a pocket next to your body. If you can't avoid this, carry them in a hip pocket where the body temperature is not as warm.
- 2) Do not leave them in a closed car in any weather.
- 3) Do not store them in a refrigerator.
- 4) Do not leave capsules or container in direct sunlight.
- 5) Do not keep them in a bathroom that becomes hot and steamy.

The controversy around AZT is likely to continue for some time. There is no clear answer. In deciding whether to take the drug, consult your doctor, research the latest studies, talk with other PWA/HIVs, and finally make up your own mind. With this drug, as with any other, monitor your reactions and report any changes to your physician.

ddI:

ddI is the other antiretroviral drug currently in general use in Canada. Studies indicate that ddI may work in cases where the virus has developed a resistance to AZT. Many people who cannot tolerate AZT seem to be able to tolerate ddI, possibly because its toxicities are different than those of AZT.

Initial trials of ddI have shown that it reduces viral activity, although it too causes side effects. The most common reported side effect to date is pancreatitis. Other early reactions have included headaches, insomnia and irritability, but these symptoms were generally mild and became less frequent as treatment continued. ddI also appears to cause neuropathy in some cases, a side effect which sometimes abates within a short time of ceasing to take the drug.

ddI is now licensed in Canada.

ddC:

Dideoxycytidine (ddC) is another antiretroviral drug which operates in much the same way as do AZT and ddI. It is too early to tell which of these drugs will ultimately be the most effective. The most common side effect to ddC seems to be peripheral neuropathy, which seems to occur more frequently at higher dosages. Other less common side effects include skin rashes, mouth ulcers, elevated liver enzymes, and low platelet counts. Studies are also beginning to indicate that ddC and AZT taken in combination may be more effective than taking AZT alone.

Clinical trials on ddC are now underway in Canada. ddC is also available in Canada through the EDRP.

Peptide-T:

Peptide-T is a new experimental HIV therapy currently being studied in the USA which shows some promise. Early laboratory results are encouraging and warrant further study.

Theoretically, Peptide-T prevents HIV from binding to uninfected cells. It is the first drug specifically designed to fight HIV infection. There is considerable evidence from the earliest laboratory tests that Peptide-T is nontoxic, possibly because it is very similar to a chemical produced by the body. Drug trials are in the Phase II stage in the United States, and several small studies have reported that Peptide T reverses neuropsychiatric symptoms associated with HIV infection and none of the participants in these studies experienced toxicity. It is a very expensive drug (approximately \$1200/gram).

Peptide-T is not currently available in Canada.

IMMUNE-BOOSTERS/MODULATORS

Immune-stimulators are designed to strengthen the immune system. While many apparent immune-stimulators exist, few have been proven to counteract the suppressive effects of HIV. So far, evidence that these drugs help is either incomplete or contradictory.

Researchers are also investigating the potential for using immune-stimulators in conjunction with antiretrovirals to counter the effects of HIV. Two immune-stimulators are currently available in Canada: antabuse and isoprinsine. There is research evidence that both boost T-cells when employed with an antiretroviral. However, it is not clear whether these drugs also reproduce the virus. People taking an immune-modulator without also taking an anti-viral agent should do so carefully and under supervision. Doctor Bernard Bihari of New York has done extensive research with immune modulators and uses them in his practice. Further information is available at the Vancouver PWA Society office.

INFECTION FIGHTERS

Most opportunistic infections are treated when they arise. Those treatments are listed under the specific infections in Section 4B. Research is now finding that there are also a few specific drugs which help to prevent several of the major illnesses associated with HIV immune suppression. Among the drugs showing promise are:

Pentamidine:

Pentamidine is one of several effective treatments for *Pneumocystis Carinii* Pneumonia (PCP) in patients with AIDS. The drug is usually administered by IV infusion. Treatment can cause severe toxic reactions including hypotension, renal failure, and hypoglycemia. Response to therapy is slow and patients require prolonged hospitalization and intensive supportive care. When treatment is given, recovery rates are high.

There are several methods for the prevention of PCP that have proven to be effective. These include bactrim/septria (Sulfamethoxazole/Trimethoprim), dapsone, and pentamidine. Aerosol pentamidine offers some advantages over the alternatives. It is a very efficient treatment; high levels can be achieved in the lungs with just a few aerosol treatments. It is well tolerated and long-term use has not resulted in significant toxicity. The major drawback to this treatment is that it affects the lungs only, whereas drugs such as bactrim provide prophylaxis to the whole system. A large number of PWAs are, or become, allergic to septria/bactrim and dapsone. Research data indicates that for people who have never had PCP, about 80% of those taking aerosolized pentamidine will never get this infection.

Pentamidine is available in Canada through the Emergency Drug Release Program for those who qualify as being vulnerable to PCP. This normally means you have a T4 count of 200 or less, although you can qualify with a higher count if recommended by your doctor.

Acyclovir:

Acyclovir is an anti-herpes drug which has shown considerable promise in several studies as a preventative for CMV (Cytomegalovirus). One study from New York reported to the Vth International Conference in Montreal that none of 60 people taking Acyclovir over a year-long period developed CMV infection, while 9 out of 14 who refused Acyclovir did. If the research is borne out, it could prove quite important as people with AIDS/HIV immune suppression are prone to CMV infections.

Acyclovir is a standard prescription drug in Canada.

Fungal Infections:

Most of the recent research on fungal infections has focused on Fluconazole and a related drug Itraconazole which are arguably more effective than traditional drug regimes, with shorter treatment periods and fewer side effects for the treatment of both candida and cryptococcal infections. Either drug might prove to be an important safeguard against cryptococcal meningitis.

ANTI-CANCER DRUGS:

Treatment and prevention of most cancers involves a combination of chemotherapy and radiation. In the case of Kaposi's Sarcoma, Alpha Interferon is now routinely used in the USA, although the response rate of KS lesions is little better than under standard chemotherapy. Doctors in the USA and West Germany are now experimenting with Beta Interferon which has fewer side effects. Both interferon products may be combined with AZT, which in itself leads to remission in some cases of KS. Another drug with reported good results and fewer side effects for KS is Pentosan, which has the added benefit of being much cheaper in the USA.

At present, a Canadian trial for alpha interferon is taking place at St. Paul's Hospital in Vancouver, and the drug is available through the EDRP. Pentosan should soon be available in Canada through EDRP.

PASSIVE IMMUNOTHERAPY:

This procedure consists of drawing plasma rich in antibodies to HIV from donors who are seropositive but healthy. This plasma is treated to inactivate HIV, then is transfused to recipients suffering symptoms of advanced AIDS.

Initial research conducted by Dr. Abraham Karpas, Assistant Director of Research, Department of Haematological Medicine at Cambridge University, as reported in the Lancet (Sept. 17, 1988) indicates that passive immunotherapy may dramatically reduce the rate of disease progression in those suffering from AIDS and HIV infection.

Generally speaking, Dr. Karpas' patients gained weight, experienced fewer symptoms, and developed fewer opportunistic infections compared with the periods before this treatment was commenced. The positive benefits from passive immunotherapy lasted from four to eleven weeks, dependent upon the amounts of antibody-rich plasma transfused. Results indicated that passive immunotherapy may be most beneficial if treatments are commenced early, before the recipient demonstrates symptoms of severely depleted T4 counts.

This program is not available in Canada. There have also been difficulties getting programs established in the US; only two or three small groups have taken place besides the above study. Attempts are currently being made for larger studies in New York City and San Francisco.

D. MEDICAL TESTS

The medical tests you take confirming you are HIV antibody positive will be the first of many medical tests you will take in dealing with this condition. In order to treat you properly, your doctor will need a constantly accurate picture of your immune system, plus how your body may be reacting to any opportunistic infections.

It would be overly lengthy to attempt to explain all the blood tests you might have to take because of HIV infection. However, there are certain basic tests you should become familiar with if you want to be better able to assess risks of disease progression and/or the effectiveness of treatments. It is recommended that tests be done regularly, say every two months, over an extended period of time, say a year or longer. When evaluated together, they can give you a clearer and fuller picture of what is going on with AIDS/HIV infection in your own body.

The blood tests normally taken are:

T4 Test:

T4 or T-HELPER CELLS are a crucial part of the immune system. The normal range for T4 cells is from 410 to 1300 per millilitre of blood. Gradual depletion of T4 cells is typical in HIV infection, but no reliable correlation between the number of T4 cells and stage of disease has been established. Generally, symptoms (other than swollen lymph nodes, which are common in infected persons at any stage) may begin to appear when T4 counts drop below about 400. There are exceptions to the general rules. While one person has developed both KS and PCP with T4 counts above 500, another has developed no major opportunistic infection to date, although his T4 count has repeatedly tested less than 50.

Researchers have recently established that T4 counts fluctuate daily, even in healthy seronegative persons. T4 counts fluctuate in response to a variety of physical states and influences. Alcohol, drugs, stress, caffeine, exercise, time of day, colds and allergies, all are suspected to influence T4 counts.

It makes sense to have repeated testing performed by the same lab under similar conditions for most accurate comparative value. But any single count, or a single aberrant count in a series, cannot be weighed too heavily as evidence of improvement or of decline (unless the count is very low, in which case it might be better to err on the side of safety). Changes in T4 counts of 20% or so may well reflect normal variations.

At present in BC, anyone infected with HIV who has a T4 count of 500 or less is eligible for treatment with AZT. Persons who have not yet commenced AZT therapy are entitled to have T-cell tests done every three months. The important thing to monitor with T-cell counts is the trend over a period of time, say one to three years.

Many doctors (and patients) rely too heavily on T4 counts in monitoring disease progression and the effectiveness of treatments. T4 counts cannot tell you whether HIV is actively replicating in your blood, or whether a particular treatment regimen is helping or not. At best, T4 counts are a vague and general marker of progression towards AIDS. But, by combining T4 testing with P24 antigen, beta 2 microglobulin, and serum neopterin testing, you can more accurately assess either the effectiveness of treatment(s), or your chances of progressing towards symptoms when you are positive and healthy.

T4/T8 Ratio:

Helper T4 cells activate various components of the immune system, while suppressor T8 cells downgrade the immune response and prevent constant immune activation. In other words, T4 cells tell the immune system when to attack an invader, and T8 cells tell the system when to stop the attack. It is normal to have a proper balance between the body's level of helper T4 cells and suppressor T8 cells; consistent stimulation of the immune system can cause significant tissue damage, while excess suppression of immune response opens the body to infection.

It is beginning to become evident that evaluating the T4/T8 relationship within the immune system may be as good, or possibly better, an indication of disease progression than measuring the T4 level in isolation. The normal T4/T8 range is from 1.0 to 3.0, while the destruction of T4 cells results in a lowered T4/T8 ratio (approximately 0.5 or less). While T4 counts can vary widely in a healthy immune system, they will generally stay in the same general relationship to T8 levels. Therefore, a widely altered T4/T8 ratio will specifically indicate damage to the T4 cells themselves, damage which is consistent with an increase in HIV infection.

The T4 fraction has proven to be a more reproducible count than the absolute T4 cell count, and therefore is a more reliable indicator of the state of the immune system. For people living with AIDS or HIV infection, a T4 fraction of 0.25 or less is a significant ratio.

P24 Antigen Test:

This test detects the presence in your blood of P24 antigen, a core protein of HIV. Since P24 antigen is present in the core of the virus, it is only produced, and only detectable, when HIV is active and replicating in your blood.

The presence of viral antigen in your blood, a condition called "antigenemia", has clinical importance. Typically, "antigenemia" - indicated by detectable levels of P24 antigen - follows initial infection. P24 then falls and becomes undetectable as your immune system commences producing antibodies to HIV. Research seems to indicate that the reappearance of detectable levels of P24 antigen in seropositive but healthy persons indicates an increased probability of disease progression.

The P24 antigen test can only detect "free" antigen. A positive test indicates the amount of P24 that has not been bound up or cleared by anti-P24 antibodies. A negative test, then, merely indicates that P24 is not "free" - that it is not in excess of anti-P24 antibodies circulating in your blood.

The efficacy of the P24 antigen test in predicting disease progression is still debatable. It is not enough to know simply that the virus is active; you must be able to tell if activity is increasing or decreasing to know if treatment is being effective. However, there is still debate about whether or not the test is really giving useful information and research is ongoing.

Beta 2 Microglobulin Test (B2M):

B2M is a substance produced in small amounts by the body under normal circumstances as a result of cell breakdown. In healthy, seronegative persons, B2M will measure less than 2.4 mg. per litre of serum. Studies have shown that B2M rises above 2.5 mg/l in HIV infection and in other chronic infections such as CMV (cytomegalovirus). The further above 2.5 mg/l your B2M count rises, the higher the level of cell breakdown within your body. St. Paul's Hospital in Vancouver uses the value of 1.7 mg/l as a scale norm.

Research seems to indicate that B2M may be superior to P24 antigen or T4 counts as a single predictor of progression towards AIDS. B2M levels do fluctuate, depending upon whether or not your body is fighting an active infection. However, it appears that regular B2M testing can help you better assess either the effectiveness of treatment(s) or your chances of progressing towards AIDS if you are positive and healthy.

Neopterin:

Neopterin is a substance produced by cells of the immune system during inflammatory disorders including viral and parasitic infections, as well as cancer. Researchers have noticed a correlation between neopterin levels and the condition of the immune system during AIDS/HIV infection. Generally speaking, the farther above normal (less than 8 nmol/L) neopterin levels rise, the greater the risk of disease progression seems to be.

Around the time of seroconversion (when previously HIV antibody negative people begin to produce HIV antibodies, i.e. test "positive") a person often has high neopterin levels without low levels of T4 cells. However, neopterin levels drop quickly once the body commences producing antibodies to combat HIV infection. From that time on, neopterin levels appear to gradually increase while T4 counts fall.

In a study of 799 HIV infected men, published in the Journal of Acquired Immune Deficiency Syndrome (1989, 2:70-76), researchers were able to predict which people had a high chance of developing AIDS based on their levels of neopterin. As neopterin levels increased, the probability of developing AIDS was shown to rise significantly. In a different study, it was

shown that a low replication strain of the virus had an average neopterin level of 12.3, while comparative blood that yielded a high replication strain of HIV had an average level of 18.8.

This research appears to indicate that measuring the neopterin level may be a quick way to assess the effectiveness of certain treatments. If the treatment is helping, your neopterin levels should fall from pre-treatment levels.

CHAPTER SIX: OBTAINING MEDICAL TREATMENT

A. YOU AND YOUR DOCTOR

A good relationship with your doctor is extremely important. As you deal with opportunistic infections arising from immune-suppression, your physician will be your caregiver and your support - ideally your partner in treating your medical condition. You should select a doctor with whom you are comfortable and in whom you have confidence. Your doctor should take time to answer your questions and deal with your concerns. You should always feel able to discuss your treatment with your physician.

If at all possible, go to a doctor who is knowledgeable about AIDS and HIV. Findings on opportunistic infections, treatments, drug benefits and side effects change rapidly and a physician working in the field is far more likely to keep abreast of current developments. In smaller communities you may have few options over which doctor to choose. In that case, you may have to educate your doctor about AIDS/HIV immune-suppression and about fears and prejudices surrounding AIDS.

The traditional doctor/patient relationship often changes when you are diagnosed with AIDS/HIV. It is to your benefit to become informed on your medical condition and treatment options. There are a number of books you can read on AIDS and HIV infection and related illnesses. You can talk with other PWA/HIVs and you can do your own research into treatments. Your doctor can interpret the medical language for you, so that you clearly understand about tests, drugs and treatments. The more you know about your condition, the more you will be able to take an active role in your own health care.

Your doctor should help you problem solve, rather than tell you what to do. You both need to feel that you can be honest with each other, and you must feel confident that your doctor has your best interests at heart. If you don't have that basic feeling of trust, you can change doctors. Don't be afraid to question, or disagree with, your physician.

It is equally important that you keep your doctor informed about the state of your health. You should keep to the schedule set by your doctor for evaluation and lab tests even when you feel well. In between visits, you may notice new symptoms and you should inform your doctor about these changes as soon as you become aware of them. In most cases, the sooner an infection is treated, the more successful that treatment is likely to be. Waiting can be disastrous. Any of the following symptoms may signify a change in your condition and should be reported to your physician:

1. **Sense of well being:** Just simply feeling less well may not really seem like a symptom, but it can be a sign that changes are occurring in your condition. Watch for a decrease in stamina or an increase in fatigue.
2. **Weight loss:** A drop in your weight of more than a pound a week, possibly accompanying a decrease in appetite.

3. **Fever:** Temperatures above 100 degrees for more than two or three days or any high spiking fevers over 102 degrees. Soaking night sweats.
4. **Respiratory problems:** Shortness of breath or persistent cough, especially when performing normal activity.
5. **Digestion:** Trouble chewing or swallowing foods because of pain. Persistent nausea or diarrhea. Abdominal pain or swelling.
6. **Skin problems:** Persistent rash or purplish spots on the skin that do not fade.
7. **Mental awareness:** Persistent headaches. Problems concentrating or remembering.
8. **Vision problems:** Difficulty focusing. Vision becoming cloudy or distorted.

Time with your doctor will be limited and you need to use it well. Make a written list of the questions you want to ask before you go for your appointment. That way you won't forget anything. If your doctor agrees, you can also have someone go with you to your appointment to write down what the doctor says, giving you an opportunity to go over his advice again later with added insight from a friend.

When your doctor prescribes drugs or treatments for your condition, it is important that you follow the prescribed dosage schedule as closely as possible. This means taking the number of pills the doctor says you should take when the doctor says you should take them. Doctors prescribe specific doses of drugs for specific reasons; it's how much and how often and how long a drug is taken that produces the desired results, not just the drug itself. It may be tempting at times to change the way you take your pills if the prescribed schedule is inconvenient, but it's not a good idea. Doubling up on medication can jeopardize your health and taking less than the prescribed dosage can also be dangerous. Too much of some drugs can poison you, while others are not effective if you don't take enough.

In addition, it is important not to take certain drugs together. For example, it has been shown that taking Dapsone and ddI at the same time decreases the efficiency of the Dapsone, which is not properly absorbed. Dapsone should be taken two hours before or after ddI. Check with your doctor or pharmacist on schedules for taking your drugs, on pill combinations to avoid, and on side effects you should be aware of.

You should tell your doctor about any alternative or "complementary" therapies you try. These therapies are not always accepted by the medical community and you should be prepared for the fact that your doctor may not support a specific treatment you want to begin. Whether or not you reach agreement on a disputed treatment, try to get cooperation from your doctor on proper monitoring through examinations and lab tests. You, in turn, should agree to heed any reasonable warning signs that come up during the monitoring process, and have the common sense to drop an inappropriate treatment if positive results are not evident.

You and your doctor are equal partners in maintaining your health. Understand and be comfortable with your treatment plan. Insist that your questions, concerns and fears be addressed. Also be aware that it is not easy for doctors and nurses to deal with AIDS and HIV infection. They too will have difficult times. Let them know from time to time that you appreciate their dedication and help.

B. TREATMENT CENTRES

As you deal with the monitoring and treatment strategies involved in maintaining your health, you will begin to consult other medical personnel and treatment centres as well as your primary physician. You may have already dealt with centres such as the lab where you get your blood work done. Others centres of care will be more specialized with specific experience in dealing with AIDS and HIV infection.

The major resource centre for AIDS/HIV care in British Columbia is St. Paul's Hospital in Vancouver, where the BC Centre for Excellence in HIV/AIDS has been established by the Provincial Government. St. Paul's has been in the forefront of AIDS care for many years and continues to be the venue chosen by the majority of AIDS/HIV specialists in the province.

While St. Paul's is the primary centre of care for people with AIDS and HIV infection, it is not the only one and is increasingly becoming a resource centre used by health professionals throughout the region who provide good care in treatment centres in their own communities. Your doctor will make the initial judgement about where to send you for specialized treatment. You can get more information on where AIDS/HIV care is available by calling your local AIDS organization.

Nonetheless, the majority of treatment and testing for conditions associated with AIDS and HIV infection occurs at St. Paul's and will likely continue to do so for some time. For example, St. Paul's is the location for a number of clinical drug trials, and is the only point of access for people wishing to participate in these trials. The current economics of health care give little reason to expect that other major centres of service will be created in the foreseeable future.

This concentration creates problems for people living outside of the Greater Vancouver area. For certain procedures, you may have to go to St. Paul's, which can mean dealing with the expense and inconvenience of travel. Transportation costs are sometimes covered by the Provincial government. Check with your doctor or local health unit for further information.

Women dealing with reproductive issues also can face a dilemma seeking care at St. Paul's as it is a Catholic hospital and certain procedures, such as abortion, are not available there. The Vancouver Women's Health Collective, the Positive Women's Network and AIDS Vancouver Island, are good sources of information on alternative centres of care.

Unless you are being admitted to the hospital, your first experience with St. Paul's will probably be through the Infectious Disease Clinic. This is where you will go for some of your blood tests, to receive certain drugs, and at times to see your doctor. This clinic is sometimes referred to as the AIDS Clinic. The phone number is 682-5060.

The Clinic is also the centre of operations for the AIDS-designated social workers at St. Paul's. These social workers can be invaluable in helping you obtain long term care, housing support, home maker services, etc. They are knowledgeable about AIDS and HIV infection and work with the hospital, medical personnel, community services, and community groups. They can also give you information on extra care and services you may be eligible for at little or no charge.

Treatment centres are like physicians - partners in your medical care. Personnel should be willing to answer your questions and knowledgeable about your condition. If you have concerns, discuss them with the centre and with your doctor. You can also raise specific problems with advocacy groups such as the Vancouver PWA Society and the Advocacy Access Project of the BC Coalition of People With Disabilities. Both groups have people familiar with the issues involved in obtaining good care.

Canadian HIV Trials Network

The Canadian Trials network was created by the Canadian Government approximately two years ago, so that Canada would have a national infrastructure for facilitating HIV Trials. The goal of the network is to make trials widely accessible and achieve the highest standards of excellence.

BC Centre for Excellence in HIV/AIDS

The BC Centre for Excellence in HIV/AIDS is located in Vancouver at St. Paul's Hospital, although it is not part of the hospital. The goal of the Centre is to establish treatment guidelines that all BC physicians can utilize. A committee of physicians and specialists dealing with AIDS and HIV infection meet regularly to discuss treatment strategies.

How to Obtain Emergency or Investigational Drugs

The Health Protection Branch (HPB) of Health and Welfare Canada has a mandate to authorize the sale of investigational drugs or other drugs which are marketed outside of Canada. Sales of these drugs are authorized to a particular physician for a particular patient with serious or life threatening illness and in whom conventional Canadian therapies have been unsuccessful or unsuitable.

In Canada, investigational new drugs are drugs that are undergoing clinical study according to strict protocols approved by the HPB.

Physicians may telephone or write to the Emergency Drug Release Program (EDRP) of the Bureau of Human Prescription Drugs in Ottawa to request an investigational drug or a drug marketed outside Canada.

After a request is received EDRP reviews the request and telephones the manufacturer to issue verbal authorization for the sale of the drug. It should be noted that manufacturers reserve the right to provide or not the requested drug. Every attempt is made to handle the request promptly and most North American manufacturers will ship the drug shortly after authorization.

Patients who are curious about the use or availability of an investigational drug should not contact EDRP but rather consult with their family physician. Physicians who are interested in obtaining information about the use of a drug, its availability, dosing or invoice arrangements should contact the manufacturer.

To write:

Head, Emergency Drug Release Program
Bureau of Human Prescription Drugs
Tower "B" Place Vanier
355 River Road
Vanier, Ontario
K1A 1W8

To telephone:

(613) 993-3105 Telephone during office hours (0830 to 1630 EST)
(613) 991-3183 Facsimile

If a drug is urgently required after office hours physicians may call (613) 991-0123 and leave a message with the message centre. EDRP staff will respond promptly.

C. GOING INTO HOSPITAL

Going to the hospital for treatment can be an easier experience if you are prepared. This section will give you an overview and some practical tips to make your stay more comfortable. Be assured, the staff of the hospital will do everything in their power to make sure that you finish your stay in the hospital rested and on the mend. Being prepared and knowing what to expect can give you more peace of mind to begin your recovery.

Being Admitted to the Hospital:

Admission procedures can be complex as there are many questions to answer, so try to be patient as this process can take a while. Take a friend with you, someone who can keep up your morale and can be trusted to start getting your affairs in order at home. While you're waiting, you can give instructions about keeping your household going. Of course it's great just to have a friend with you for support.

To make admission go smoothly, bring your Medical Insurance card, and the name and contact address for the Ministry of Social Services and Housing financial worker whom you have been dealing with. This information on your record will ensure that your stay is paid for, that you will not suffer an interruption in your income and that arrangements to get you home can proceed without a hitch.

You can be admitted either through the Hospital's Emergency Department, or through the Admissions desk. If you come through the Emergency Department, be aware that at times the department will be very busy and that personnel do not deal with patients in order of arrival, but give priority to patients needing immediate medical attention.

If your Doctor refers you to the hospital, report to the Admissions desk during regular office hours.

Accommodation:

The hospital assigns patients to rooms on the basis of availability of beds, and medical need. You may be moved as beds become available or priorities change. It is possible you will spend some time in a bed in the Emergency ward or some other ward until a suitable bed is found for you in the ward best meeting your care needs.

Types of Hospital Accommodation:

If you wish to stay in a private room, it will cost you a considerable amount extra out of your own pocket, unless you carry supplementary medical coverage which pays for private accommodation. Be sure to check your insurance for this coverage before you are admitted to the hospital. If you carry supplementary insurance, you may be able to receive this benefit through paying an extra fee as set out in the policy.

If you are prepared to pay the cost or have appropriate insurance coverage, be aware that assignment to a private room is subject to availability - medical need has priority. For instance, special procedures or contagious infections may require that a patient be isolated from other patients.

If the hospital assigns you to a private room for whatever reason, relax, you won't be asked to pay an extra fee.

Two-bed rooms may be the most private available in certain wards. Patients with AIDS or related medical conditions are most likely to be given an assignment to share a room with one other person with a similar condition.

In some wards there may be up to four beds in one room, but it is considered very unlikely you will be assigned a bed in such a large room.

For some medical procedures such as blood transfusions or intravenous drug treatments, your stay in hospital may be short, or limited to day time hours on successive days. Rather than actually admit you to the hospital, your physician may send you to Medical Day Care, which is set up to provide short term beds. Be aware though that you can be kept there overnight if it becomes medically necessary.

The Palliative Care Unit provides beds for those who no longer wish aggressive treatment. A patient can enter Palliative Care when they are in the last stages of illness. The Unit also provides respite care to patients, allowing them to spend time in hospital and gather strength and then return home as they choose. It is quite common for people to enter and leave Palliative Care a number of times over many months as their health dictates.

Your Medical Progress:

Take responsibility for your role in the healing process. Remember you are a full partner in carrying out your treatment plan to get well. By ensuring you know what to expect every step of the way, you can monitor how you are doing and can act to improve your progress. Discuss, negotiate, insist on the best care, including being fully informed, from those carrying out your treatment plan.

Learn exactly why you are being admitted. What can you do that will help? Learn what the plan is for your hospital stay, what treatments and procedures you will undergo and any necessary preparations that you will need to make. How long will you be in the hospital?

Be sure that your own doctor knows as soon as possible that you are being admitted to hospital if you are checking yourself in, and take with you the information that hospital staff will need to contact your physician. Be aware that you may have a different primary care doctor during your stay if your physician does not have admitting privileges at that hospital.

It is very important you know who decides what concerning your care so that you will be able to ask questions, make suggestions, and discuss your care with someone who can make necessary changes. Who will see you? What treatments and procedures will you undergo and how does the outcome of these affect the rest of your treatment? How long are you likely to be in hospital, and what might happen that would change this estimate?

What specialists are you being referred to and what role will they play in your care? Especially, find out who you must ask to learn about the various aspects of your medical progress.

With knowledge comes the ability to take responsibility for your own recovery and retain control over your own life, so ask questions and insist on answers that make sense to you!

Medication:

Know what medication has been prescribed and why, so you can check whether, in fact, it is having the desired effect. Since medication can come in a bewildering variety of forms, insist on knowing what specific kind or brand name is to be given, how it will be given and on what schedule. Knowing this allows you to monitor to avoid mistakes. Consider that you're the only one who knows everything that you're taking and be alert to the possibility of interactions between drugs.

Your own medication from home may be brought in but will be placed in safekeeping, because for safety reasons all drugs, including those you bring, must be administered by hospital staff. Ensure your doctor knows what you're taking, so that undesirable interactions between drugs can be avoided.

Interns and Residents are likely to be assigned some aspects of your care, as most hospitals are teaching institutions and hands on experience is an essential part of the training of new doctors. Any decisions these personnel make are subject to review by their medical supervisors. If any difficulty arises, your primary care physician can help.

Decisions About Your Care:

You can arrange in advance to appoint friends or family to act for you as a committee if you are in a position where you cannot make your wishes known concerning your care. This is best done by preparing a "Living Will" (see Chapter III). Be sure that those whom you appoint clearly know your wishes beforehand. If you do not designate someone to act for you, decisions on your care will be made by your next of kin instead of by the person you might prefer. A legal form called 'Enduring Power of Attorney' will enable someone to act for you when you cannot be consulted.

Your Rights:

You have the right to be fully informed on all aspects and decisions that affect your care. It is up to you to take as active a role as you can to exercise these rights. Be prepared to ask questions, discuss and negotiate the conditions of your recovery.

You are entitled to be fully informed as to all possible consequences before you give your consent for any tests, procedures or medication. Insist on knowing the medical treatment plan for your stay, the diagnosis of your condition, and the expected outcome of your stay in the hospital.

Medication Rights:

You also have the right to be fully informed on the medications you are given and why, to be told how they will be administered, and on what schedule. Determine what side effects may be experienced, reasons the medication or procedure might be adjusted, and especially reactions which would require that this treatment be discontinued. You have the right to accept or refuse medications or treatments, but in making that choice, you should consider the possible very serious consequences of not following the doctor's prescription. For this reason, insist on receiving the best and fullest information from your caregivers. This is your right.

Testing:

Expect to know the reasons for whatever tests are done for you and how the outcome might affect your care. You should be told how to prepare yourself and whether there might be some discomfort involved. You have the right to know the results of tests, including the medical interpretation as this affects your care. Insist on knowing the results.

Rights of Refusal:

You can say NO to any test, medication or procedure, but doing so could have serious consequences. Discuss your concerns with your primary physician and any specialists involved, and be sure you are fully informed about the implications of your decision. Explain very clearly why you want not to undergo certain tests, procedures, and ask how your decision not to proceed might affect the plan for your treatment. Be very sure you understand the reply. Ask questions and do not make a decision on the basis of poor or incomplete information.

You can choose to leave the hospital on your own initiative but you should discuss your intention with the medical personnel in charge of your care, as you need to be aware of the medical consequences of not continuing under hospital treatment and supervision.

You have the right to limit visits by student doctors in training, but it is wise to discuss this with your doctor before admission. It may benefit other patients in the long run if you can cope with this intrusion or arrive at some sort of compromise. The hospital has a responsibility to provide new doctors with the chance to care for patients under supervision, and they certainly need training and experience in treating people with AIDS/HIV-related conditions.

You can see all visitors, some visitors or no visitors as you choose. You have the right to arrange with the nursing staff to have your visitors screened. It is not rude to limit a visitor's stay, or to ask them to leave if the visit becomes too taxing. Your first priority is to get well, not to be the perfect host. At the same time, hospitals can be very understanding about giving your partner, family or caregiver open access to you if you wish. You can make these arrangements with the nursing staff or with your physician.

Hospital Staff:**Doctors:**

Depending on the circumstances of your admission, your regular doctor may be a visitor without privileges at the hospital to which you have been admitted. In this case, your primary physician for your stay will be a specialist or a doctor assigned by the hospital. It is important that you know who will make decisions about your care and that you can make your wishes known to that physician. Ideally, your hospital physician will also consult with your regular doctor to ensure your treatment is consistent and comprehensive.

Specialist Physicians:

Should your medical condition warrant it, a specialist may be called in to care for you. As with any other person involved in your care, this physician is a partner with you in your recovery. Discuss your condition and insist on your right to be fully informed on decisions affecting your care. This means knowing which concerns are to be brought to the specialist's attention, and which will be referred to your admitting physician. Knowing who has the power to decide on which aspects of your care will enable you to retain a voice in those decisions.

Lab Workers:

Some testing procedures are performed by Laboratory Technicians who have special training in the complexities of medical test procedures. They may come to your bedside, or take you to be tested in the lab on machines such as the x-ray, Ultrasound or CATscan, which are too large or complex to be brought to your room. You can ask the technicians about preparation and procedures which will make the testing go smoothly, but medical questions about the results and their interpretation are best directed to the doctor who ordered the tests.

Social Workers:

At St. Paul's Hospital, AIDS knowledgeable social workers are available to assist you during your stay in the hospital and during your recovery at home afterwards. They will make every attempt to get to you within 24 hours of your admission, and can help you make your stay go

smoothly. If you are on income assistance, GAIN or HPIA, let the hospital social worker know how to get in touch with the Financial Aid Worker who looks after your case, so your income can continue without interruption and any special needs can be dealt with. If you need to apply for assistance, the hospital social worker can help.

Other services the hospital social worker can provide or arrange for you include:

- Counselling service: this may be arranged on self referral, in person or by telephone.
- Patient Advocacy: If you are dissatisfied with any aspect of your care, the social worker can intercede for you.
- Home support: Practical home care assistance or financial assistance can be arranged through the Ministry of Social Services & Housing.
- Discharge Planning: The social worker can arrange for home nursing care, alert other agencies to arrange services, and liaise with the BC Ministry of Social Services and Housing.

Dietary Aides:

If you have special dietary concerns, you can arrange to have your meals planned according to the requirements of your special diet and medical needs with the help of a Dietary Aide. People who have spent time in hospital tend to recommend the vegetarian diet plan for general reasons of taste and variety.

Pastoral Care Workers:

To offer comfort and help with religious and spiritual matters, Pastoral Care Workers are available. If you want a say in who visits you, you can specify your religious preference at the time you are admitted, which will ensure that a pastoral care worker of your religious persuasion is told you are in the hospital. The pastoral worker can put you in touch with your own church and arrange for visits by clergy, or can talk with you on matters related to your spiritual life, or offer comfort and a friendly ear.

They are prepared to help and comfort your caregivers as well, and can arrange for practical assistance if needed, such as a place to stay in a church member's home for family members from out of town.

If you prefer, you can specify that you do not wish to be visited by pastoral care workers.

Cleaning, Maintenance Staff:

Cleaning and maintenance activities can sometimes be rescheduled by discussing your concerns with the nursing staff. Alternately, you may arrange to be out of the room for tests or physiotherapy when repairs are to be made nearby or when the cleaning staff does your floor. This is where learning the routine of the hospital can pay off because the place really thrives on routine.

The hospital electrician must inspect and approve every appliance you bring with you that plugs into the hospital electric system.

Comforts:

A few simple comforts from home can make a big difference to your stay in the hospital. Bring a favourite pillow from home, a quilt or comforter in bright colours, your own drinking glass, a teddy bear - whatever will make your stay a little easier for you.

Bring your own clothing, such as robe and pyjamas, or your own bedding. Display pictures of yourself in a state of health with your loved ones. Hang up posters and greeting cards by your bedside with the help of your visitors. A guiding thought is that you want the people who care for you to see you as someone who has a life beyond the hospital, so that you will be well treated as a person. It also helps you to feel more relaxed if your surroundings feel at least somewhat familiar.

Music can make a big difference, so bring your radio, walkman, or discplayer; music; headphones (a must, out of consideration for other patients); batteries and charger. The Vancouver PWA Society has machines and tapes which are available on loan to members in hospital.

AIDS Organizations Hospital Outreach:

The Vancouver PWA Society has volunteers available to run errands or pay you visits if you would like, but you must tell the hospital staff to contact the Society for you.

The Society can arrange to contact relatives if you wish, and can arrange for counselling for you or your caregivers.

Visitors:

You have every right to control the number and timing of your visitors and you will find the hospital staff can assist you by screening visitors at the nursing station. Remember you are there to recover your health, not to entertain people as if you were in a state of perfect health. Set

limits and ask your visitors to leave if you become overtired. This is not selfish, it is self preservation.

Phone Calls:

It feels good to hear the voice of a friend. In the hospital, you can usually find a pay telephone down the hall which is available at all hours. A few rooms have phone jacks installed and these may be usable if you are unable to get out of bed. Ask the nursing staff what arrangements can be made.

Pets as Visitors:

It may be possible to have your cat or dog brought to certain wards to visit you, by special arrangement. This is not possible in every ward, so check with the nursing staff before bringing your pet into the hospital.

Food:

There is just no substitute for your favourite food, whether it is good home cooking or a meal from your favourite restaurant. You can ask friends to bring you food in clean lidded containers which can be utilized for fridge storage or microwave use. The Patient's Lounge may have a refrigerator and microwave for your use. Subject to dietary considerations, you can have your visitors bring fresh fruit, veggies or other treats - anything at all you would enjoy.

Television:

Rental TV units are available with cable service included in the rental cost. Your nurse can have the sales person come to arrange installation of a set at your bed.

You can bring your own set, but it must be approved by the hospital electrician before you can plug it into the hospital's electric circuits. A CSA sticker is required to show that your set meets the safety requirements of the Canadian Standards Association. Battery power is ok but its plug-in charger must have a CSA sticker and be approved by the hospital electrician.

Unfortunately cable service alone is not available for your own set; it is only available as part of a TV rental contract.

The Home Front:

Keep the home fires burning warm for your return; your recovery will progress with fewer worries if you have provided for your household's smooth running in your absence.

Find a responsible person to look after your household in your absence and give them a set of keys. A trusted friend or relative can arrange care for house plants and pets. Have your friend check regularly that your home is secure if there's nobody living there in your absence. Ask them to keep an eye on your mailbox and to bring your mail and magazines from home. They should also cancel papers, and any regular deliveries, so your full mailbox won't tip off a thief that nobody is home. Your friend can also bring any bills that need to be paid, and your chequebook for you to sign if you are well enough. If you are too ill to see to paying your bills on time, have your friend alert your creditors that you are in hospital, not derelict in meeting your obligations.

You can give someone the authority to act for you when you cannot act by arranging an enduring power of attorney as described in Chapter III. A trusted friend or relative can pay bills and your rent, deal with banks, insurance companies, and your employer.

Notify friends you wish to visit you by having one friend call the rest from a list or address book prepared in advance.

Planning for Discharge:

Before you are discharged from the hospital, there are some things you should set up so you can recuperate comfortably at home. Your hospital Social Worker can offer a range of services which will help you continue your recovery. Discharge Planning can include such services as notifying your friends and family when you will be discharged and helping them get ready to bring you home.

Home nursing is available to ensure that you have ongoing nursing care in your home as you need it. This can include procedures such as changing bandages or administering medication by injection.

You can get help through home-making services to keep your house tidy, do the laundry or prepare meals.

There is a Buddy Matching service available upon request from AIDS Vancouver to find a suitable person to come to keep you company and go with you to help you run your errands. This service is meant to help people feel less lonely, so Buddies are chosen and trained more to be good listeners and companions than to provide homemaking services. Sometimes a good friend to talk to can make all the difference while you get better at home.

A Summary Pep Talk:

You have been admitted to the hospital to get better under the care of dedicated, caring professional health care workers, but never forget that you are a full partner in your care. Don't be shy or afraid!! You have every right to be heard in all decisions that affect your care. Speak up, ask questions, try to become fully informed. You'll have a less stressful and perhaps shorter time in hospital as a full partner in your care.

Even so, your hospital stay may take longer than you would like and this may not be when you would like to take time away from your normal life. Hospital life can be full of frustrations. However, hospitals also contain some wonderful people whose job is to help you get better as soon as possible. Patience and forbearance are needed here. As you learn and adapt to the routine of the hospital, you can also learn how to promote your own return to health as rapidly as possible.

D. MY DOCTOR AND I

The following article was written by Kevin Brown and published in the March 1988 issue (# 18) of the Vancouver PWA Society newsletter. Kevin died on May 17, 1989 after years of coping with AIDS. The article is being reprinted verbatim. Kevin remains a very alive presence to us all and his relationship with his doctor, Brian Willoughby, endures.

"MY DOCTOR AND I"

Or Learning to take care of one of your best friends

by Kevin Brown

I have now been living with AIDS for 33 months - not a record by any means, but I'm proud of it, considering the odds. It's hard to know what keeps me going. I feel like that Timex commercial, sometimes - "takes a lickin' and keeps on tickin'". I'm sure that my success to date comes from my positive attitude, treating my disease aggressively (but not obsessively), remaining focused and active, and, undoubtedly, my relationship with my doctor, Brian Willoughby.

My doctor and I, over these past 33 months, have certainly developed a close bond, forged by this disease. He has experienced some pretty intense scenes, both in his office and at the hospital, when the "Drama Queen" in me felt so inclined to act out. I sometimes wonder if we sound less like doctor and patient, and more like two old lovers going at it. It is a bond of mutual respect, admiration, trust, loyalty, heartache, laughter and love.

With this in mind, it should follow that the doctor takes care of me, and if I acknowledge my relationship with him, then I have some obligation to take care of him.

This concept was first brought home to me about a year ago, as poor Brian and I went through a particularly "dramatic" scene. I was sick again (as usual, suffering an assortment of ailments). I felt so bad, I thought I would have to rally in order to die - basic shit on a stick. It was hard to remember what "well" felt like. Both my patience and my temper were wearing thin. It was with this cheerful mood that I entered Brian's office, wanting nothing less than my total cure, for I had had enough of this disease! After all, he is the doctor, and isn't that what doctors are supposed to do? Cure people? As you might suspect, I was far from reasonable, and when the inevitable happened (he didn't cure me!), a row ensued.

Looking back I can see that the "little boy" in me (that little boy that is in all of us), was angry and in pain. All my little boy wanted was for someone to hold him and kiss everything better - like mother used to in those distant Donna Reed like days of my childhood when life certainly seemed easier. The reality of the situation is that there are no easy solutions, no magic bullets from any doctor. I'm in this fight for the duration, and I have the responsibility to accept and get on with it.

That day in the doctor's office a lot of crap came out that was directed at Brian. He was the easiest target to lash out at - representing that sacrosanct medical authority that couldn't do a damned thing for me. He became my whipping boy without a thought for his feelings. This was not a role that Brian accepts willingly, and I was soon set straight. He was prepared to accept my misguided rantings that I dished out so freely, only as long as he thought they were of some benefit to me - to let me get it off my chest so it won't hurt so bad. Only I had to realize that he, too, was human. There was only so much shit he could take which he felt wasn't justified. He is more than a doctor, but also my friend. I didn't want to, or like, hurting him. The scene finally ended with mutual tears and hugs, followed by my exit.

Since then, I have been thinking about the strain on all the AIDS Care Team doctors. The above little scene in Brian's office was hard enough on me, and I'm sure, one that repeats itself constantly, creating an accumulative effect on these doctors that must be devastating. Doctor burn out becomes a very real problem, one that PWAs might also have to face. What do we do if our doctor has to leave because of the strain? Dr. Hilary Wass left partly because of burn out, proving the problem is real.

What I need to know is, who gives care to the caregiver? And once I have identified the problem, how can I effect a solution? I must first change my attitude - to see my doctor as a human being with similar needs as I, not as some medical God. I need to say "thank you" more often, give hugs, smiles, send flowers even. Any one of a thousand things that might make his day easier. Maybe you should too.

E. OBTAINING MEDICAL TREATMENT FOR THE PHYSICIAN AND PATIENT

This chapter has been included to offer an 'optimal accelerated care model' to the physician who may have few HIV/AIDS patients in his practice but does not specialize in this area. This information will also be of use to the individual who would like to take a more active role in his or her care and work in partnership with his physician. Please take this information to your physician and share it with him or her.

OPTIMAL (ACCELERATED) CARE

GOALS: To provide compassionate, effective, cost sensitive optimal (accelerated) care and prevent further transmission of the disease.

STRATEGIES:

- 1) Intervene with antiretroviral medication at the appropriate time.
- 2) Offer prophylaxis against certain opportunistic infections especially *Pneumocystis Carinii* pneumonia (PCP) and others at correct times.
- 3) Early diagnosis and offer of treatment as quickly as possible.
- 4) Offer new experimental antiretroviral medications, immune system modulators, or experimental prophylactic medications at the appropriate points.
- 5) Finally offer appropriate palliative care for untreatable disease.

ASYMPTOMATIC H.I.V. PATIENTS:

- Visit physician every three to six months.
- As patient becomes symptomatic or a helper count falls more frequent examinations are required.
- Patients taking AZT, DDI, DDC should be seen at least monthly.

EARLY TO MODERATE H.I.V. DISEASE:

- Numerous clues are to be found in the regular history, medical exam, and laboratory evaluation which will alert the clinician to the need for closer scrutiny and follow-up.

SYMPTOMS:

- Mild on-going malaise
- Some anorexia and mild weight loss
- Sense of easy fatigability
- Development of new dermatology disease such as psoriasis, recurrent folliculitis, seborrheic dermatitis
- Recurrent Herpes Simplex disease
- Outbreak of Herpes Zoster
- Respiratory disease such as recurrent sinusitis or development of lobar pneumonia
- Gastrointestinal disease might include occasional diarrhea with bacterial parasitic organisms found as the cause.
- Non-specific muscle and joint pain transient in nature

LAB STUDIES:

- Decreasing absolute helper count
- Decreasing fraction of helper cells
- Increased IgA
- Increased Beta2 microglobulin and increased immune complexes

OPTIMAL ACCELERATED CARE: EARLY INTERVENTION:**DIAGNOSTICS: BASELINE STUDIES:**

- 1) Complete Blood Count
 - a) RBC - Red Blood Cell count
 - b) WBC - White Blood Cell count
 - c) MCV - Mean Corpuscular Volume
 - d) Platelet count
 - e) Hemoglobin
- 2) Biochemistry
 - a) Liver Function
 - b) Kidney Function
 - c) Amylase
- 3) Immunologic Follow-up
 - a) helper and suppressor count
 - b) helper/suppressor ratio
 - c) % of helper cells
 - d) Beta2 microglobulin
 - e) P24 Antibody
 - f) Neopterin

- g) P24 Antigen
- 4) Gynecologic Diagnostics:
 - a) Pap Smear
 - b) Colposcopy
 - c) Routine STD Cultures
- 5) Routine STD Cultures for both Males and Females:

PROPHYLAXIS IN EARLY INTERVENTION:

Vaccines:

- a) Pneumovax
- b) Flu shot
- c) Hemophilus Influenza B
- d) Hepatitis B

Prophylaxis:

- a) TB
- b) Herpes Simplex
- c) PCP

MODERATE TO SEVERE H.I.V. DISEASE:

Symptoms:

- Worsening constitutional symptoms as fevers, night sweats, weight loss
- Worsening seborrheic dermatitis or psoriasis
- Development of facial warts or molluscum contagiosum
- Severe recurrent Herpes Simplex
- Progressive periodontitis, gingivitis, or hairy leukoplakia
- Severe persistent sinusitis
- Mycobacterium TB disease of the chest may be reactivated
- Diarrhea often accompanied by considerable fluid depletion and weight loss
- Peripheral sensory neuropathies
- Subtle decrease in cognitive function and memory may be seen
- Sense of fatigue and malaise frequently worsens

Laboratory Studies:

- Anemia
- Leucopenia
- Neutropenia
- Non-specific changes in liver function studies
- Decreased absolute helper counts

- Depressed percentage of helper cells
- Increased elevation of Beta2 microglobulin
- Positive P24 antigen test

SEVERE HIV DISEASE:

Is heralded by the onset of all AIDS defining opportunistic diseases and malignancies.

Lab Studies:

- Anemia
- Leucopenia
- Neutropenia
- Depressed absolute helper counts
- Depressed fraction of helper cells
- Increased Beta2 microglobulin

The presenting illnesses in ninety percent of HIV+ patients in BC who go on to a diagnosis of AIDS are the first four of the following list:

- Pneumocystic Carinii Pneumonia
- Kaposi's Sarcoma
- Esophageal Candidiasis
- Mycobacterium Avium Intracellular
- Toxoplasmosis of the brain
- Cryptococcal Meningitis
- Primary Lymphoma of the brain
- HIV Encephalopathy
- Wasting Syndrome due to HIV
- Immunoblastic lymphoma
- Cytomegalovirus disease, especially of the retina, adrenal glands, digestive tract or spinal cord
- Chronic Intestinal Cryptosporidiosis
- Chronic Herpes Simplex Disease

DIAGNOSTICS FOR PROPHYLACTIC INTERVENTIONS:

- 1) Toxoplasmosis
- 2) CMV (experimental)
- 3) MAI
- 4) TB
- 5) Hepatitis A & B
- 6) Syphilis
- 7) Cryptococcal meningitis

PROPHYLAXIS:

- 1) PCP
- 2) Candidiasis
- 3) Toxoplasmosis
- 4) MAI
- 5) CMV
- 6) Cryptococcal meningitis

AGGRESSIVE TREATMENT OF OIs (Opportunistic Infections):

- 1) PCP
 - a) Septra/Bactrim
 - b) Intravenous Pentamidine
 - c) Clindamycin & Primaquine
 - d) Dapsone & TMP
 - e) 566C80
 - f) Other antibiotics
- 2) CMV/Herpes
 - a) Acyclovir
 - b) Ganecyclovir
 - c) Foscarnet
 - d) experimental agents (oral)
- 3) TOXOPLASMOSIS
 - a) Pyrimethamine & Sulphur
 - b) Pyrimethamine & Clindamycin
 - c) 566C80 (experimental)
 - d) Dapsone (in combination therapy only)
 - e) Chinese Herbs
- 4) MAC/MAI
 - a) Ciprofloxacin + Rifampin + Amikacin + Clofazimine + Ethambutol
 - b) Clarithromycin
 - c) Liposomal Gentamicin (not available)
 - d) Rifabutin
 - e) Azithromycin
- 5) CRYPTOCOCCAL MENINGITIS
 - a) Amphotericin B
 - b) Liposomal Amphotericin B (not available)
 - c) Fluconazole

- d) Itraconazole
- e) New Antifungals (experimental)
- 6) CANDIDA
 - a) Ketoconazole
 - b) Fluconazole
 - c) Echinacea
 - d) chetrimazole lozenges
- 7) DIARRHEA
 - a) Imodium
 - b) Narcotics (Lomatil or tincture of opium)
 - c) Beta Carotene
 - d) Sandostatin (experimental)
 - e) Erythromycin and Immune Booster
 - f) Spiramycin
 - g) Colostrum (experimental)
 - h) Diclazuril
- 8) KAPOSI SARCOMA - EXPERIMENTAL
 - a) Cimetidine
 - b) AGM 147U
 - c) Minocycline
 - d) Hyssop (herb)
- 9) KAPOSI SARCOMA - STANDARD
 - a) Radiation
 - b) Liquid Nitrogen
 - c) Chemotherapy
 - d) Interferon - alpha
 - e) Interferon - alpha and AZT

COMBINATION THERAPY:

- 1) Combinations of Antiretrovirals
- 2) Combination of:
 - a) Antiretrovirals
 - b) Immune Boosters
 - c) Prophylaxis for OIs
 - d) Nutritional Program

PROMISING AND EXPERIMENTAL THERAPIES:

Cimetidine (Tagamet), Hyssop (Plant), D.N.C.B., Clarithromycin (Antibiotic), Hypericin (Plant), TAT Gene Inhibitors

CHAPTER SEVEN: LOOKING AFTER YOURSELF

A. STAYING HEALTHY

When you have AIDS/HIV, staying well is a major concern. Maintaining health means more than just treating infections as they occur. There are a number of ways you can take care of yourself. In fact, there are so many possibilities that you will have to make some choices about what works for you.

The use of complementary therapies, in particular, is highly individual. These will be discussed in detail further in the chapter. You may try all of them; you may try none of them. Whether or not you choose to experiment with alternatives, there are common-sense steps you can take to keep yourself well.

Rest:

One of the common symptoms of AIDS and HIV infection is fatigue. This tiredness may come and go, and it may include a loss of energy as well as drowsiness. Frustrating as coping with this may be if you are used to getting by with little sleep, pay attention to your body's need for more rest. This does not mean you should become a hermit and cease to have a social life. Far from it. What it does mean is that you may have to restructure your lifestyle to allow for a little more quiet time.

Lifestyle:

On the other hand, don't feel you need to give up everything you care about doing because you have AIDS/HIV. You may find no change in your health for a very long time. Your body will give you clear signals that it requires more rest or anything else, for that matter. In the meantime, it is important you stay connected with the things that make your life satisfying. Make changes as you feel you want to. Rest. Eat well. Pay attention to the signals from your body. Use common sense, but continue taking part in activities you enjoy.

Exercise:

Some kind of exercise, if you feel up to it, can be relaxing, energizing, and can put you in a positive mental space. But you don't have to go for a ten mile jog or heavy workout in the gym. Do what you can. Try swimming (easy on the body), a short walk, a stretch class or a bike ride if you're feeling particularly good.

Tai Chi, an ancient Chinese technique of meditation through movement, is a gentle exercise that helps balance the energy through the body. Yoga also provides moderate exercise, stretching and relaxing your body, as well as calming and focusing your mind. On the other hand, go to

the gym and take aerobics if you'd rather. Any exercise will tend to reduce anxiety, tension and depression, as well as improving your physical condition.

Dehydration:

One key thing you can do to stay healthy is to make sure you drink enough fluids. Dehydration (lack of fluid in the body) can make you feel unwell and it can easily occur as a result of even mild conditions, such as diarrhea, vomiting and excessive sweating. Symptoms can vary from thirst and decreased appetite, to accelerated heart rate, nausea, exhaustion and hallucinations. The severity of the symptoms will depend on the percentage of total body water that has been lost.

Dehydration can be prevented by drinking six to eight glasses of water per day and watching your diet. Water is absorbed faster and more effectively if it is consumed on an empty stomach. Drinking ice water and drinking water with meals will both interfere with your digestion.

Infections:

When your immune system is compromised, it is important to report any infection, even a cold, to your doctor. Opportunistic infections are more easily treated when caught early. Minor infections like cold and flu can also be more easily dealt with if you take immediate care. Colds or the flu are no more dangerous for people with AIDS/HIV than for anyone else. However, nurturing yourself against minor illness is a good idea. You might consider taking a flu shot each winter and should certainly take more rest and liquids when you have a cold. Feeling ill is draining, even if it is not threatening. Talk to your doctor, take care of yourself, and pay attention to how you feel.

Recreational Drugs:

The key here is moderation. Sensible amounts of alcohol do not appear to have an adverse effect, but regular high intake can suppress your immune system. Alcohol can also interact with certain drugs in ways that can be damaging.

Smoking will irritate your lungs and interfere with immunity. Many common opportunistic infections also affect the lungs. This is one habit you might consider cutting down or quitting all together.

Other recreational drugs may also damage your immune system or other parts of your body. For example, there is evidence that cocaine may cause HIV to multiply more quickly than it would do if not stimulated. It is a good idea not to overdo things, and to pay attention to any adverse signals your body sends you. In this, as in all other aspects of your health care, you must make your own choices.

Vaccinations:

When you have AIDS/HIV immune suppression, you can theoretically be at risk from live vaccines (such as polio) and should therefore avoid them. All killed vaccines and flu vaccines are safe and can be taken with no risk. If you are travelling, remember to specify no live vaccines.

Long Term Survival:

Although absolute predictors do not exist, there are certain attitudes towards self-care which appear to be common among long term survivors. These include:

- Taking personal responsibility for your health and treating your doctor as a collaborator.
- Being assertive and having the ability to say "no".
- Being able to nurture yourself.
- Being sensitive to your body and your psychological needs.
- Being able to communicate openly about your needs, including your illness.

Evidence is beginning to show that your attitude toward your health can be as important as many of the self-care steps you take. Be good to yourself. You'll feel better for it.

B. NUTRITION

One of the best ways you can help yourself stay healthy is to eat properly. Dealing with AIDS/HIV will place extra demands on your body and your body will need more and better nourishment to properly cope. In general, the better your eating habits become, the better you are likely to feel and the healthier you are likely to remain.

Malnutrition is a very common, and often unrecognized, problem for people with AIDS and HIV infection. As with any chronic, debilitating disease, dealing with AIDS and HIV infection increases nutritional requirements, and several AIDS/HIV-related infections specifically interfere both with intake and absorption of nutrients. As a result, though you may be eating "normally", you can still be suffering from malnutrition.

There are many conflicting theories about proper nutrition, but most nutritionists agree that eating fresh, whole foods will help cleanse and strengthen your body. However if your diet has been inadequate up to now, you may find that making the switch to eating healthier foods is not

easy, especially if you are not feeling well. Introduce changes to your diet slowly, giving your eating habits and your digestive tract a chance to adjust. You can also start reading about nutrition and diet to give yourself an understanding of the food you eat and its effect on your body.

Nutritionists agree that you should eat balanced meals, including fresh and cooked vegetables, fruit, dairy products, whole grains (rice or cereal), and moderate amounts of meat, preferably poultry and fish. Eating one of cabbage, broccoli, carrots or brussels sprouts each day may be particularly good as these vegetables contain substances that are believed to be anti-cancer agents. Wash all fruit and vegetables thoroughly before eating to remove traces of pesticides or any germs. If you can afford it and have a choice, and have a health food store nearby, buy organic fruit and vegetables. Meat, poultry and fish should be well done to kill off any bacteria. Some nutritionists argue that you should avoid red meat, while vegetarians advocate you avoid meat entirely.

Chewing your food thoroughly and eating products containing fibre helps your digestive tract to cleanse itself properly. This is particularly important as your digestive tract may be working more slowly than normal. However it may be wiser to avoid bran muffins; the cooked fibre can be hard on the stomach.

To improve your digestion, try yoghurt, acidopholis supplements, and digestive enzymes (all of which can be obtained at a health food store). Non-yeast based B vitamins are good for digestion as well. These should be taken with your meal. Try to drink six to eight glasses of water daily to cleanse your body. This amount of liquid is also needed for normal digestion. Coffee and alcohol tend to dehydrate your body and are not substitutes for adequate water.

As a PWA it is very important you maintain a high intake of calories. You should average between 4,000 and 5,000 calories daily. This is about twice what you would normally need. Don't worry if you gain a bit of weight - look on it as an insurance policy. However, eating more may pose some problems of its own. Many PWAs suffer from lack of appetite for a variety of reasons, including infection, depression, fatigue and nausea. Food may taste terrible at times. This is a common problem if you are taking certain antibiotics. If you have candida albicans (yeast) coating your taste buds, it will probably make your food less tasty. Intestinal parasites and bacteria can interfere with your digestive process, and can cause diarrhea, constipation, or both of these alternating.

The best way to increase your intake of calories is to eat smaller meals and eat more frequently. Carry snacks with you. Your appetite may be better in the morning. If so, try to get at least one third of the day's calorie and protein requirements in what you eat for breakfast. You can even eat your dinner meal at breakfast time if that will help.

If your appetite is small, try using nutritional supplements such as high protein milkshakes. These can be expensive, but if you are on handicapped pension you are entitled to some of these products for free. You can arrange this through your doctor. If you are not on handicapped pension but have minimal income, your social worker may be able to arrange for free

supplements for you. If you have problems digesting milk-based products, and cannot drink the dairy-based liquid protein supplements, try soy-based products, yoghurt or soy milk instead. Ask your doctor, nurse or nutritionist for recipes for nutritious milkshakes.

Eating high protein cold food such as cottage cheese or cold soups may be a solution when you have nausea around food, or an altered sense of taste. Avoid greasy or fried foods and limit spices when you have mouth sores. Go easy on foods containing sugar (desserts, chocolate, soft drinks, etc). Sugar may feed the yeast in your body and can make active yeast infections worse. It is widely believed to unbalance your system. Beer is also thought to feed yeast.

If you have diarrhea, you should have your doctor test you for parasites. Diarrhea can be dangerous and parasites can be treated with antibiotics. It is also possible that you may have a lactose intolerance, causing diarrhea. (Lactose is a milk sugar found mainly in dairy products.) When you are dealing with diarrhea, avoid high fibre diets (which are good for constipation), fried or greasy foods, and meats. Choose bananas, mangoes, and diluted orange and nectar juices to replace minerals you may be lacking.

In general, you should try to drink less caffeine. (Caffeine is found mainly in black tea, cola drinks and coffee.) Caffeine robs your body of many necessary vitamins, particularly B vitamins. If you can afford one, buy a juicer and make carrot and beet juice. These juices are good sources of pure, quick, concentrated vitamins, particularly beta carotene. Beta carotene is a vegetable form of vitamin A and is used as a cancer therapy.

Maintaining a nutritious diet can feel like a stressful production, particularly if you live on your own and/or have a reduced income. Friends can help. For example, you can cook up several servings of a particular dish together then portion it out between you. You can also learn about cooking things like pasta and beans which have comparatively high nutritional value relative to their cost.

Alternative Diets:

You may want to experiment with alternative food regimens, such as macrobiotic or naturopathic diets. Some people report they have been able to stabilize AIDS/HIV infection following a macrobiotic diet. Various local groups periodically hold classes on this type of cooking. If you choose to follow this kind of diet, you will have to become much more aware about what you are eating. For example, if you are on a vegetarian diet, you must learn about how to get enough protein, particularly if you do not eat eggs or dairy products.

If an alternate diet works for you, great. But be realistic. If what you are eating does not result in weight gain or maintenance, then it is not the diet for you. Keep your medical team informed about any diet you are on and take their advice into account.

For further diet information, you can call DIAL-A-DIETITIAN for free professional advice. The number in Vancouver is 732-9191. There is also a province wide toll free number at 1-800-667-3438.

C. COMPLEMENTARY THERAPIES

There are many advantages to complementary therapy treatments, but the process of deciding who to see and what method to choose can be confusing. The range of complementary therapies is wide. Some people swear by megavitamins and others will only consider Chinese herbs and acupuncture. Particularly in this area, a method that is helpful to one person may not necessarily be useful to someone else. It can be frustrating, time consuming and expensive shopping around to find out what, if anything, works for you.

Before you make a decision, research the treatment. Talk with people who have used it. Interview one or more health practitioners. Determine if the treatment makes sense to you. Is the practitioner a caring person who listens to you, someone you feel you can trust? What is their experience with AIDS and HIV infection? Avoid practitioners who directly, or indirectly, blame you for being ill. Beware of those who tell you they have the one and only cure. Forget about extremists and fanatics.

Most of these methods attempt to restore a state of balanced energy to the body, and to eliminate toxins from the body. The basic aim of these healing disciplines is to create an environment where healing can occur naturally. The assumption is that there are emotional, mental and spiritual aspects to any disease, and that there is much that you can do to heal yourself. Their approach is more to build up the body's general health, rather than to fight a specific virus or fungus.

There is a middle ground between depending on drugs and doctors, and taking a totally "holistic" approach to treatment. Many PWAs choose to combine aspects of both approaches, using herbs and vitamins for example, and following a good diet, along with taking antibiotics. This can be a very successful approach, as long as you let each of your health practitioners know what other kinds of treatment you are following. Always be sure your physician knows of other treatments you are taking, as these treatments may interact with prescribed drugs.

The following alternative therapies have proven useful to other PWA/HIVs:

Traditional Chinese Medicine:

Traditional Chinese Medicine is a complete, organized medical system, the second largest in the world. It is not to be confused with folk medicine or with hucksterism. In China, Japan and South East Asia, it is recognized as an official component to be integrated with, not supplanted

by, the practice of Western medicine. Such an integrated policy was adopted by the People's Republic of China in 1949 and by the Japanese government in 1976.

Herbal formulas are central to Traditional Chinese Medicine, but they are not the only TCM therapeutic measures available to AIDS and HIV patients. In the holistic approach characteristic of TCM, acupuncture/moxibustion, manipulation (Chinese massage and chiropractic adjustment) and Qi Gong (meditation) have all been used in treating AIDS and HIV infection with especially beneficial effects in relieving symptoms and improving the quality of life.

Carotene/Vitamin A:

Carotene is the plant form of Vitamin A. Carotene has been linked to cancer prevention, and studies have indicated that it is a protective agent against lung, stomach, bladder, esophagus, and throat cancer. Good sources of carotene are carrots, apricots, broccoli, asparagus, winter squash and sweet potatoes.

Vitamin C:

Vitamin C is a natural substance which is known to build up the body's general resistance to infection and act as a detoxifying agent in the blood stream, eliminating toxic substances from the body. Because of the toxicity of the modern environment, proponents of this treatment, including Nobel Prize winner Dr. Linus Pauling, recommend doses of 4000 mg per day as maintenance for an average healthy person, and substantially more for someone dealing with illness or immune suppression.

Vitamin C can be taken in capsule or in a powdered form mixed with water or fruit/vegetable juice. It is water soluble and stays in the body for only four to six hours. There are no serious side effects if you use more than you need. Most of the side effects are gastro-intestinal discomforts, including diarrhea, which can be alleviated by decreasing the vitamin C dosage. Calcium ascorbate seems to upset the stomach the least. Experiment and listen to your stomach until you find a form and a dosage that works for you.

It is important to note that people taking the drug "Septra" (a PCP prophylaxis) should not be taking large quantities of vitamin C at the same time, as this combination appears to be hard on the kidneys. If you are taking or considering "Septra", consult your doctor about taking Vitamin C at the same time.

Other Essential Supplements include vitamin D, vitamin E, zinc, essential fatty acids such as found in olive oil, B6, magnesium, cod liver oil (for its high A and D as well as other factors good for the circulatory system), copper, manganese, niacin and selenium (which has some anti-cancer properties in minute quantities). Remember, whenever you take one of the B vitamins you should always take a general B complex, too.

The following is a basic food list for vitamins and minerals:

Vitamin A:	eggs, cheese, butter, milk, and vegetables that are yellow, orange, and dark green.
B Vitamins:	wheat germ, sunflower seeds, safflower oil, almonds, oysters, whole-grain cereals, noodles and bread, fish, milk, dark green vegetables, nuts, beans and peas, and kidneys.
Vitamin B6:	sunflower seeds, wheat germ, tuna, whole-grain cereals and bread, avocados, spinach, green beans, and bananas.
Vitamin C:	many fruits and vegetables, including berries, citrus fruits, tomatoes, melons, green peppers, potatoes, and dark green vegetables.
Vitamin E:	vegetable oils, whole-grain cereal and bread, wheat germ, dried beans, and green leafy vegetables.
Bioflavonoids:	(eat these with vitamin C) lemons, grapes, plums, black currants, grapefruit, apricots, buckwheat, cherries, blackberries, rosehips, and prunes.
Folic Acid:	wheat germ, kidneys, dark green leafy vegetables, and bran.
Iron:	kelp, dark molasses, wheat bran, pumpkin and squash seeds, wheat germ, liver, lean meats, dried peas and beans, whole grains, dark green vegetables, eggs, shrimp, oysters.
Potassium:	bananas, peaches, broccoli, yams, potatoes, squash, nuts, sunflower seeds, garlic, halibut, herring, sardines, lentils, whole grains, kelp.
Zinc:	milk, shellfish, herring, wheat bran, and split peas.

Herbal Therapies:

Health food stores carry a number of herbal therapies which are advertised as being valuable for various conditions. As with anything else which affects your health, do some research on side effects and interactions with other substances, and proceed slowly. Many herbs have serious side effects when taken in the wrong dosage. The watchword is 'be careful'.

Blue Green Algae:

Super Blue Green Algae is a natural food supplement high in vitamins, trace minerals and amino acids, which is harvested in Southern Oregon. Proponents say it significantly increases a person's energy level and provides greater mental alertness, that it reduces the effect of stress on the mind system while balancing out the physical system's functioning, and that it serves as a detoxifier and immune system enhancer.

Visualizations and Affirmations:

Visualization techniques for healing have been used by various cultures since ancient times. Visualization involves relaxing, and feeling at one with the symbol, scene or process you imagine. It is a skill to be learned, and some people will find the process easier than others. There are books, tapes and classes which can teach you the technique.

Affirmations are a way of daily confirming, out loud or in writing, the positive aspects of your life, and of reaffirming the goals you set for your health. Again, there are books, tapes and classes which teach this technique.

Other Methods:

Other major holistic healing methods include shiatsu, chiropractic (along with applied kinesiology or muscle testing), massage and bodywork, Reiki and homeopathy. Many PWAs seem to benefit from some kind of bodywork. Touching can feel very supportive, and can help break down emotions of fear and isolation.

A Healing Circle is held weekly at St. Paul's Hospital in Vancouver, for PWAs, their friends and lovers. The volunteer leaders of this Circle use a variety of healing methods: visualization, laying on of hands, singing, affirmations, and many PWAs find support through the strength of the group.

The best way to get information on complementary therapies, is through research and word of mouth. There are a number of good alternative bookstores and healing magazines on the market, and the libraries at the PWA Society and AIDS Vancouver carry books on many areas of alternate therapy. It is also useful to talk with people who have used the therapy you're interested in and to compare their experiences. You can also contact holistic organizations directly, and meet with practitioners before making a commitment to try any particular therapy.

D. MY EXPERIENCE WITH ALTERNATE THERAPIES

The following article was written by Warren Jensen in the Spring of 1989. Warren died on September 16, 1989, after living with AIDS for four years.

"MY EXPERIENCE WITH ALTERNATE THERAPIES"

by Warren Jensen

When I was diagnosed with Kaposi's Sarcoma (KS) and pneumocystis pneumonia (PCP) in October 1985, there was no AZT, and the medical establishment could offer help fighting infections, but nothing to fight the virus.

PWAs were looking for anything that might extend their lives, and I was soon one of them.

I went to a homeopath, heard promises, spent lots of money, and took the remedies. Six months later I said goodbye to homeopathy.

I started taking vitamins - no mega doses. I still take them. I explored meditation. Carl Simonton's book, "Getting Well Again" was my start. Then an intensive weekend learning how to relax and meditate at HOPE: the Cancer Help Centre in Vancouver. I learned a lot there and met some wonderful people. I followed this up with a biofeedback session that convinced me of the mind-body connection.

I used to be the kind of person who ignored his body when it called for rest or food. We had to do this, this and that first. I learned to listen to my body, and care for it better. I now feel connected with my body for the first time.

I took a class called Energy Awareness, which focused on the body's energy systems.

I don't meditate regularly as I used to. But I send my body loving, healing messages all day long. I know how to relax and wash away stress and worry. I explored this area of health enhancement and kept what worked for me.

I read about Iscador, an immune boosting preparation made from mistletoe. I got some from Switzerland. It came in tiny glass vials, to be injected into a muscle once a day for eight weeks. I practised with a syringe and an orange and asked myself, "Do you really want to do this?" The Iscador sat in my fridge for two years before I threw it out.

I know now that boosting T cell production is a mistake, unless you can attack the virus at the same time. You may produce more T cells, but that will just offer the virus more places to replicate.

Around me, other PWAs were exploring diet and meditation. Some were scrambling for Ribavarin and Isoprinosine from Mexico as the price rose steadily. Louise Hay was growing in popularity. Her message of "love yourself" and "heal your body" is a good one. I draw the line at "love your lesions". I prefer to hate and kill my KS lesions.

Some were taking mega doses of Vitamin C. Others felt herbs were the answer. I brewed Tahibo tea for a while. Next it was crystals, properly cleansed in the sea. The most amazing properties were attributed to crystals. After a while we started to joke, "Got a problem? Eat a crystal!" I still have a crystal in my AZT bottle, as a keepsake of those times.

We leafed through "Common Ground" and invited therapists to talk to us about their beliefs. After the macrobiotic lecture I tried a few of the meals, and soon agreed with Taavi Nurmela when he said, "No thanks, I'd rather die!"

I did go on a nutrition trip for several months. To cleanse my body I cut out all dairy, fat and red meat. Chicken, fish and steamed vegetables were the order of the day. Complex carbohydrates rather than sugar, and low protein, were the rule.

I hate cooking. I'm not good at it. Now I was in the kitchen more often than I cared to be. Friends would invite me to dinner, describe the menu, and ask, "Can you eat that?"

I grew to hate broccoli, and miss beef and milk. My weight continued to creep down. I went home for Christmas, ate my mother's heavy food for two weeks, gained 5 lbs and felt a lot better. I came home and started eating everything. That diet was more stress than benefit. I started AZT at this time and soon I was gaining a kilo per week.

I gained back all my weight and energy. I even got a little chubby before levelling out. Does anyone need a pair of 34 waist acid wash jeans?

Now I eat for calories. This may horrify some readers, but it works for me. I eat any food that appeals to me. I remember how I scoffed at the advice of Mrs. Drummond, the nutritionist at St. Paul's Hospital. Here's the voice of experience when she says, "Snack all day. Eat animal protein at every meal. If you don't get those calories in, you will continue to lose weight."

I read an article in the "New York Native" about syphilis and AIDS. I ran to the STD Clinic for the specialized tests which they happily administered. All came back negative.

When AZT became readily available, I was amazed to see how interest in alternate therapies quickly waned. It seemed that we'd all rather pop a pill than do any work on mind-body development.

I tried AL-721, the egg lecithin extract. After a couple of months I quit. I didn't feel any difference. Recent research summaries on AL-721 say it doesn't appear to work.

I recently was taking Dextran Sulphate (DS). I read a couple of articles hyping the possible benefits. The October 1988 "Scientific American" said DS "probably inhibits viral activity". So I started on it because it was cheap, available and non-toxic. After two months I quit. I didn't feel any of the benefits that had been touted. Recent reports from studies in San Francisco say that only 1% of the DS actually gets into your bloodstream - not enough for me!

Nowadays, friends are exploring ozone therapy, typhoid shots and transfusions from healthy carriers of HIV. I'm glad someone is trying something new. I wait and watch to see what happens, rather than jumping in early on. I want to be sure I do no harm to myself. New therapies will continue to appear regularly, accompanied by hype and hope. Your task is to sort through them and find which you want to try - if any! Then be realistic about quitting, when benefits don't appear.

We are all facing this new disease together. It's not easy fighting for life in uncharted waters. Give me a disease where patients and physicians have a long experience dealing with it. Then the choices for better health would be clear. Instead, with AIDS, we are all learning together. Charting one's personal program can be daunting.

Looking back over alternate therapies, I would say that some helped and some didn't. But all of the people who got busy and explored better health did better than those who were passive and depressed. Those who were busy got a sense of empowerment when all of the news about AIDS was bad news. Those who were busy smiled, loved, hugged and shared with newcomers the desire to stay alive. They knew they were participating in their getting well.

No one dropped their physicians to chase a magic cure. Partnership and honesty with one's physician works best. Who cares if you do or don't actually live longer when you get busy about being well? Quality of life improves dramatically. You've got a mission - caring for your body and mind. You find reasons to stay alive. You meet others in the same boat, who give you information, encouragement and comfort.

It's a good way to live.

E. CLOSENESS AND INTIMACY

Intimacy is an essential part of human life. PWA/HIVs are sexual beings whose lives and expressions of sexuality become highly complicated by the virus and its ongoing problems. It is common for someone newly diagnosed with HIV infection or AIDS to abstain from sex for some time. Returning to sexual intimacy is one of the larger challenges faced by PWA/HIVs and HIV positive people face crucial difficulties with sexual intimacy. The fact that HIV is easily transmitted through unprotected sexual intercourse often makes sexual activity feel like a taboo.

Sexual expression is natural and should not be stopped simply because you are HIV positive. However, it is crucial for both you and your partner that you practice safer sex. Certainly you do not want to infect your partner. It is equally important that you protect yourself against being exposed or infected with any other sexually transmitted disease. AIDS/HIV is just one of many dangerous STDs; others include gonorrhoea, syphilis, herpes, chlamydia, and parasites.

The basic principle of safer sex guidelines is to avoid the exchange of body fluids. Sexual fluids and blood have been shown to transmit HIV. Other body fluids (urine, saliva) can potentially transmit other diseases (hepatitis, CMV, Epstein-Barr virus, herpes) but no transmission of HIV has been shown to occur due to kissing, licking, nibbling, etc.

Oral-genital contact (blow jobs, etc) appears safe if all surfaces are free of cuts, sores or bleeding. Cumming in someone's mouth, and swallowing semen is not recommended, although the actual risk is unknown. It's difficult to get HIV and simple to minimize and eliminate the exchange of sexual fluid and blood: don't share needles, wear a condom whenever there is penetration, cum outside your partner ("on me, not in me").

People often choose to abstain from sexual activity for a period of time. Others don't miss a beat. Testing HIV positive means you carry a potential killer with you in the bars, on the streets, at work and play, and in bed. A lot of people feel they need to be honest and inform their partner(s) about HIV positive status. Most people agree that it's imperative that everyone play safe, so there is no unknown risk behaviour.

Certainly disclosing your status puts a strain on every relationship. If you don't know the person well, there is the possibility of cruel rejection, breach of trust and recrimination. Even if you are close or old friends, there may be feelings of fear, suspicion, guilt and anger. Everyone feels the fear of AIDS, and the urge to survive. There is a lot of ignorance about AIDS and HIV infection - be prepared to carefully explain the whole thing, from the beginning, each and every time, for everyone. Disclosure is something that needs to be carefully thought out and presented. Our own individual fears and insecurities will prejudice and perhaps needlessly inflame someone else's concerns and fears.

If sex was an important part of your life before you had AIDS/HIV, there is no reason to stop now, providing you take precautions to protect yourself and your partner(s). Wear a condom and use either a water-based lubricant such as KY Jelly. There have been many reports that prolonged use of spermicidal jelly or condoms containing "Nonoxynol 9" can cause skin irritation, which can increase the risk of HIV transmission. A dental dam can be used for protection in oral-genital contact.

Do not share sex toys.

It is important that you maintain close relationships of all kinds and there are many forms of intimacy which do not involve direct sexual contact. Close social contact involving touching, embracing and kissing carries no risks. If you enjoy touching, do not deprive yourself or others

of this way of expressing your feelings. Pay attention to your need to give and receive love.

There are a few don'ts to keep in mind. Do not share toothbrushes, toothpicks, water picks or dental floss as they can carry small amounts of blood or mouth infections from person to person. Razors should not be shared as they too can carry small amounts of blood. It is also wise not to share towels, washcloths, etc. There is no risk of spreading HIV this way, but other infections can be passed on. The basic principle should remain not to share articles which involve body contact. This is one area where it's best to play safe.

F. HOUSEHOLD HYGIENE

While you should not become paranoid about picking up infections from normal household waste nor be frightened about passing on HIV through normal day to day living, there are certain precautions you should take to protect yourself and those you live with from infections. In general, be careful not to come in contact with body fluids and be aware of particular types of household waste which may be potentially dangerous.

Cleanliness Around the House:

Normal standards of hygiene will reduce your risk from household infection. Hot water and disinfectant cleaners both kill germs and it is advisable to use both. Use rubber gloves to guard against infection (as well as to protect your hands from harsh cleaners) and use different cleaning cloths for kitchen and bathroom chores. Wash clothes and bedding in the washer or at the laundromat in the normal way. Any items soiled with body fluids should be washed separately.

Most household waste can go in the garbage as usual. Used tissues, small dressings, etc. can be safely flushed down the toilet.

Dealing With Body Fluids:

Whenever possible, clean up after yourself. If someone else helps you, they should wear rubber gloves and dispose of any blood, vomit or excrement down the toilet. After, clean all surfaces (but not skin) with a solution of one part bleach to ten parts water.

If you inject, be careful to safely dispose of all needles, syringes and other equipment. Do not re-use or share needles. If you must re-use, thoroughly sterilize all equipment and store between uses. A used needle can spread HIV and other infections.

If you have a accident that causes you to bleed, wash the wound thoroughly in soap and hot water, then dry and cover it with a waterproof bandage until a scab forms. Anyone helping you when there is blood around should wear rubber gloves. If someone else gets your blood on their

skin, tell them to wash thoroughly with soap and hot running water. If they have an open cut or sore, they should encourage the wound to bleed, wash it with soap and hot running water, dry the area, apply a mild antiseptic if possible, and cover the area with a waterproof bandage until a scab forms. You should follow exactly the same procedure if someone else's body fluid comes near an open sore or cut of yours.

You must never donate blood, semen or any other parts of your body unless they are to be used solely for AIDS research. Blood donation forms in BC have a area to be checked off if you feel obligated to donate blood (say as part of a blood drive at work) and at the same time, wish to have your blood disposed of. The safest option is to avoid donating blood entirely if at all possible. Never carry an organ donor card.

Safe Pet Guidelines:

Recent studies have indicated that pets often have a positive influence on the quality of life. However, when you have AIDS/HIV, you may also run the risk of catching infections from your pet. This makes the question of keeping a pet more complicated, but does not mean that you should not have a pet.

The decision to keep your pet is personal and should be discussed with your physician. By following safe pet guidelines you can minimize the risk of catching diseases from your pet.

1. Wash your hands after handling your pet, especially before eating or smoking.
2. Clean up all messes (vomit, urine and feces) with a disinfectant and wash your hands. Wearing disposable rubber gloves provides extra protection.
3. Keep your pet's nails short to minimize scratches. If you are scratched, wash thoroughly with soap and water and disinfect. If swelling or redness develop, contact your physician.
4. If you are bitten, wash thoroughly with soap and water and disinfect. If swelling or redness develop, contact your physician.
5. Be careful if you are around kittens, puppies or strays, especially if they have diarrhea. Young animals or strays are more likely to be infected with a zoonotic disease, compared to a well-cared for pet.
6. Do not adopt monkeys, "exotic" animals or animals thought of as wild; they are more likely to bite and may carry unusual diseases.
7. Planning for the future will help to minimize stress and insure that your pet is not neglected. Make arrangements with someone who can care for your pet if you are temporarily unable to do so, and devise a way to notify that person in case of an

emergency. Arrange in advance for a permanent home for your pet in the event that you can no longer keep it.

8. Use disposable cat box liners and change them each time you change the litter. Wear rubber gloves if you must deal with the box yourself.

G. HOME SUPPORT SERVICES

No matter how well you take care of yourself, there may be times when it is difficult for you to manage on your own. There are a number of services available which can make it easier for you to cope when you are not well or when you simply haven't the energy to take care of your household.

Home Care Nursing and Long Term Care:

Home care services are generally funded by the Provincial Ministry of Health and operate through local health units. Home care nursing includes services such as medication and symptom management, assistance in obtaining and using special equipment, post-operative care at home, assessment and advice regarding household adaptations, home hospice care, and general nursing support. There is no charge for nursing and rehabilitation services, although there can be a charge for equipment.

Long Term Care services can include homemaker services, household assistance, and adult day care services. If you receive GAIN, there is no charge for Long Term Care services. If you are on other pension or working, the department will undertake an assessment of your income to determine what, if any, portion of the daily cost you will be responsible for.

Health units advise people with AIDS and HIV infection to register with them as early as possible. It is not necessary to actively need care in order to begin this process. From the time of registration, it can take up to two weeks for an assessment to be completed. By pre-registering, clients ensure that they will have immediate access to services if and when needed.

Meals on Wheels:

Meals are prepared and delivered to those who are unable to make their own food. Clients, regardless of age or income, may refer themselves or be referred by social services agencies, doctors, families or friends. There is a small fee charged for each meal. The program operates in most areas from Monday to Friday. Check your telephone directory white pages under "Meals on Wheels".

Because of special diets required at times by people with AIDS and HIV infection, other meal resources have begun to be developed specifically to meet these needs. Check with your local AIDS organization, or with the AIDS-designated social workers at St. Paul's Hospital in Vancouver for further information. You may also be eligible for an extra food allowance under GAIN to meet special needs.

Obtaining Special Equipment:

The Kinsmen Rehabilitation Foundation operates an equipment loan program which allows for the permanent loan of communication aids, environmental controls, wheelchairs, patient lifts, and other items. The service is available to anyone in need of the equipment. You can contact the Foundation at 2256 West 12th Avenue, Vancouver, V6K 2N5 (736-8841).

Equipment may also be available through your local AIDS organization or through your health unit.

Grocery Shopping:

The North Unit of the Vancouver City Health Department (1651 Commercial Drive, 253-3575) operates a volunteer shopping service for people who cannot leave their house to obtain groceries or drugs. Residents of east Vancouver and the downtown east side only are eligible for this service. Check with your local health department for a similar service in your area.

AIDS service organizations frequently run programs which provide volunteers to perform similar errands. Check with your local AIDS group for further details.

Finally, check your local grocery and drug stores. Many smaller, independent markets provide delivery services to their customers at little or no charge.

Transportation:

One of the most difficult dilemmas to solve in caring for yourself can be finding inexpensive ways to get around. If you are receiving GAIN for Handicapped, you are eligible for a one-year, unlimited use bus pass at a minimal cost. This will allow you a full year of unlimited travel on your community transit system. To receive a bus pass, make application directly to the Ministry.

If you are receiving GAIN for Handicapped, have a valid driver's license and own or lease a car, you may be eligible for either or both provincial and federal gas tax rebates. For information call Vancouver 666-4664, Victoria 388-3377. A 25% reduction on insurance premiums can be obtained by people who qualify for the Provincial Gasoline Rebate. Check with your local ICBC agent.

To obtain a placard for access to designated parking spots close to buildings and other facilities, contact SPARC, 106-2182 West 12th Avenue, Vancouver BC V6K 2N4 (736-4367). Current fee is \$6 and the placard is valid for 3 years. You can also obtain meter exemption stickers in Vancouver through Vancouver City Hall. To be eligible, you must have the need to park in the city centre on a regular basis. To obtain an application form, contact Traffic Engineering, Vancouver City Hall, 873-7338.

Physically disabled persons who travel with an attendant can obtain an ID Card which will allow their attendant to travel for free on motor coach and rail lines. The ID Card and certificate of eligibility can be obtained from the Kinsmen Rehabilitation Foundation, 2256 West 12th Avenue, Vancouver BC V6K 2N5 (736-8841). People with disabilities and their attendants can travel for half fare on BC Ferries with the presentation of a BC Ferry ID Card. To obtain this card, you need to provide a doctor's letter to BC Ferries, or to selected community groups such as the Kinsmen or the Canadian Paraplegic Association. At present, this 50% reduction does not apply to vehicles.

Most airlines allow attendants to travel for half fare when a traveller has provided a doctor's certificate.

For more information on transportation benefits, contact the Advocacy Access Project of the BC Coalition of People With Disabilities at Local 872-1278 or Long Distance (toll-free) 1-800-663-1278. Or contact your local AIDS organization.

CHAPTER EIGHT: WOMEN, CHILDREN AND AIDS

A. ISSUES FOR WOMEN

Finding out you have tested HIV antibody positive or have AIDS can be a very difficult experience, and there are some factors that make it even more so for women. Traditionally women are the caregivers of children, partners, other family members and friends. Caregiving may be part of your occupation. So even if you are healthy, you can be faced with many more problems and stresses when you think about the future and living with HIV infection or AIDS.

Knowledge about the effects of the virus on women's bodies is still haphazard, reflecting the fact that, until recently, the overwhelming percentage of those infected in North America have been men. Likewise, most of the women who have had HIV infection and AIDS on this continent have been poor women of colour (Black and Hispanic) in the United States. The problems faced by Canadian women with AIDS and HIV infection are not accurately represented in either case, and it is important when looking at the information available to remember these factors. For example, poor women in the U.S. have far less access to health care, and, as a result, their immune systems may already be functioning at a low level when they seek care. The picture of the disease presented by these women is far more severe than it might be for a woman with consistent access to good medical care.

At the same time, there are certain issues which effect all women living with AIDS and HIV infection. Childcare, pregnancy, housing, lower incomes, and feelings of powerlessness around these issues tend to be a common ground. Many women have not been part of the same type of community used so effectively by many gay men with AIDS and HIV infection to organize and draw support. This often means having to work harder to make connections with other women with AIDS/HIV. Yet as gay men have shown, this kind of peer support can be crucial. Other women with AIDS and HIV infection, although they may lead very different lives from yours, will understand your feelings and problems. Finding these women may be an important step in gaining more power over your own situation.

B. SEXUALITY

An essential part of dealing with AIDS/HIV centres around the virus' transmission and its tie to sexuality. You may never know exactly how you got the virus, or you may have a partner who is positive, ill or has already died. Your partner may be negative and need to be protected, or you may have no partner at all. It is possible you have had to contact former partners about exposure.

Having an illness so closely associated with having sex can be sexually immobilizing, even if the virus is contracted through needles or blood. Some women continue to have sex and some do not. Some decide to change their sexual activity, others to communicate more openly about sexual relations. You may have to assert yourself about 'safer sex' in a way that's new and possibly more difficult for you.

Having AIDS/HIV will only add to feelings of anger, low self-esteem, and depression, and will strengthen fears of losing love and being abandoned. Amidst these very negative and self-destructive feelings, it can be difficult to see the experience of an illness as a challenge to grow. Yet it has been shown that emotions are somehow connected to the immune system, indicating that finding strength, learning to love and appreciate yourself and having a more positive attitude may help you physically as well. Getting past self-critical feelings may help you fight AIDS/HIV and put your life in better order. While there is no one way in which to achieve this end, participation in things such as support groups, individual therapy, twelve step programs, education and counselling around issues may be helpful. For some disclosing to close friends and family can help you sort things out.

Human beings need warmth and emotional support, and most of the time, we desire intimacy in our lives. Whether you are heterosexual or lesbian, there are fairly easy guidelines you can follow to make it easy to maintain relationships and intimacy:

Safe and Safer Sex:

Safe sex is about making smart choices and staying healthy. It means showing love, concern and respect for your partner and for yourself. It means enjoying sex to the fullest without transmitting, and/or acquiring, sexually related infections. Safer sex does not mean having to eliminate sexual passion and intimacy from your life. What it does mean is reducing the chance of acquiring HIV infection. For those of you who decide to engage in sexual intercourse, reducing the risk of HIV infection means using latex barriers every time you have intercourse.

If you do not have anal, oral or vaginal intercourse, you have almost no risk of HIV infection. Saliva, sweat, tears and urine do not transmit HIV, but semen, blood and vaginal/cervical secretions do. Activities that involve direct contact with semen, blood or vaginal/cervical secretions are risky and allow for the transmission of the HIV. Precautions that reduce the chance of direct contact with those fluids will make sex safer.

Activities such as talking, fantasy, touching, massage, kissing and licking along with masturbation (as long as the skin any of these fluids comes in contact with is unbroken) are considered to be no-risk/low risk behaviors.

Oral sex (fellatio) with a man is considered low risk but is uncertain given that pre-ejaculatory fluid may contain HIV; the potential for transmission does indeed exist. The same holds true for oral sex with a woman (cunnilingus). The risk for acquiring HIV seems very low but is uncertain. Cunnilingus during menstruation may have more risks associated with it given the potential for the presence of blood at this time.

The risk of HIV transmission during oral-anal contact is uncertain, but thought to be low. The use of a dental dam during cunnilingus and oral-anal contact, and a condom during fellatio further reduces any possible risks.

Unprotected vaginal or anal intercourse is seen as a very high risk behavior in terms of allowing HIV to be transmitted in what is thought to be the most ideal mode for transmission. Latex condoms used along with adequate amounts of water-based lubricants significantly reduce the potential for transmission of HIV.

Lubricants are very important because they will reduce the risk that the condom will break during vaginal or anal intercourse. Be generous with the amount of lubricant used; you can never use too much and always use water based lubricants such as KY Jelly. Oil based lubricants may cause the condom to weaken or break; never use them with a condom.

Condoms do not provide 100% protection against transmitting or acquiring HIV; however their proper useage will provide the most effective protection available. Remember to always use latex condoms with a reservoir tip (to collect the semen). It is possible to be allergic to the spermicidal coatings used or the lubricant, so experiment with different brands to decide which ones you prefer.

Always put the condom on the erect penis before any vaginal or anal contact occurs, and keep a spare handy should the one you are using break. A separate application of lubricant or spermicide in the vagina or anus may provide additional protection should the condom break or slip off. Ensure that your partner removes the condom while his penis is still fully erect to prevent either slippage or spillage. Dispose of used condoms; never reuse condoms!

Alcohol and other recreational drugs do not cause HIV infection; however they are often major factors when people have unsafe sex. Safer sex takes some planning, thinking and negotiating. Alcohol and drugs can impair your judgment, cloud your thinking and limit your ability to communicate effectively. They may also make you clumsy and careless in the proper useage of condoms and lubricants.

Women Who Have Sex With Men:

When you have AIDS/HIV, it is important to use a condom for vaginal or anal intercourse for several reasons. First, you must protect your partner from exposure to the virus and ideally, your partner should be aware of your status. Even if your partner is also antibody positive, it is important that neither of you is exposed to more "virus load", that is, more virus or a different strain of virus, from each other.

Condom use is equally important to guard against exposure to other contagions. Your immune system can be increasingly compromised by trying to fight other infections. There is some indication that infections such as syphilis, for example, need more treatment (longer or higher doses of drugs) in the presence of HIV. Herpes can also be a more problematic infection in people with AIDS and HIV infection; longer and more frequent outbreaks necessitate larger amounts of drug therapy to control the herpes virus. If you haven't been using condoms and have been exposed to any infection, or are having symptoms such as vaginal discharge, see your doctor right away.

Condoms can be a part of very effective birth control when combined with contraceptive foam, diaphragm or cervical cap. Other methods have more potential problems. IUD'S carry the risk of infection, and the hormonal effects of the pill on a woman with AIDS/HIV are not known. As always with birth control, weighing the safety and effectiveness of a method has to be balanced by what you are comfortable using.

Women Who Have Sex With Women:

The risks for the sexual transmission of HIV between women is unknown, although the risk is believed to be minimal. As with all of this, the risk factors increase given the greater degree of risk taking behaviors involved. There is no estimate for the number of women (let alone lesbians) infected with HIV. Further complicating this area is the presence of co-factors such as needle sharing, multiple sexual partners and, prior to 1985, blood products.

Common safer sex advice involves supporting you to talk with your partner about their past sexual partners and lifestyle history. Initiating this discussion can be difficult; however one suggestion on how to approach this issue is to practice what you need to say either alone or with a friend. This hopefully will allow you to discuss the issues you need to in an appropriate way. Safer sex is an individual responsibility; low risk activities will not protect you if you continue to engage in the occasional high risk activity. Remember, it is believed that HIV can be transmitted by any high risk behaviors at any time.

C. INFECTIONS IN WOMEN WITH AIDS/HIV

Not much is known about AIDS in women. Although we are now beginning to see the emergence of trends and diagnostic similarities there is very little understanding of what these trends mean. For example, Kaposi's Sarcoma (KS), the purple skin cancer that affects some men with AIDS, is less likely to occur in women. On the other hand, women seem more susceptible to respiratory infections. Because AIDS and HIV infection in women have not been recognized until recently in North America, there is some dispute about how comprehensive and applicable to women the criterion used to confirm a diagnosis of AIDS really are. Many women seem to die before having any of the infections or cancers that result in an AIDS diagnosis. For this reason, there is suspicion that the number of cases of AIDS in women are being under-reported.

Women with AIDS and HIV infection need special gynecological care. Recurrent vaginal infections or pelvic inflammatory disease (PID - inflammation of the tubes and ovaries) are not uncommon. Vaginal infections need regular attention. You should probably have Pap tests done every 6 months; and if your results are Class 2 or higher you should also have a colponcopy. (A Pap test is a sample of the cells on the cervix which is checked for abnormalities). It is also important that your doctor check for papilloma, a kind of wart virus, which is becoming more

implicated in cervical cancer. Generally, more viral infections emerge when the immune system isn't functioning normally.

D. REPRODUCTIVE HEALTH

Much basic information about the effects of AIDS and HIV infection on reproductive health is not known. Previously, pregnancy was thought to increase the risk of accelerating the course of AIDS. At the moment, this does not appear to be true in a healthy woman. Nonetheless, most medical advice cautions against pregnancy or advocates delay. However, even postponement may add to the woman's risk of never having children. In either case, the need to make this decision may create a profound sense of grief or loss.

A woman with AIDS/HIV who chooses to become pregnant or to continue a pregnancy sometimes faces tremendous opposition from family members, health care providers and the community. She also has to endure a long wait before knowing whether her child is healthy.

Whether or not a woman decides to terminate her pregnancy does not appear at this time to be totally dependent upon her HIV status. The literature does not highlight HIV/AIDS as a sole reason for making the decision to terminate a pregnancy.

Current statistics indicate that 25% or less of babies born to mothers with AIDS/HIV will contract the virus during pregnancy. 70% of babies will remain free of the virus. To some extent, the baby's status seems to vary according to the mother's health, but there is no way to predict in individual cases. If one child has contracted the virus during pregnancy, the chances seem to increase that another child will follow the same pattern.

All babies are born with the mother's antibodies in their blood, mixed via the placenta. These antibodies protect infants from infections that the mother has been exposed to until the infant's own immune system begins to take over during the first year of life. Even when the infant has not contracted the virus during the pregnancy, the HIV antibody acquired from the mother can remain in the child's blood for 15 months or longer. This can be a long wait to determine whether the baby is infected.

The child should be tested immediately after birth, although a positive result is likely. Later testing should occur at intervals both the mother and health care providers feel comfortable with. In many cases, the child is not tested again until one year of age. A negative test at this time should indicate that the child is virus free, but it is wise to test the child every so often to be sure as tests are rarely 100% accurate.

One of the key safeguards of your child's health will be finding a doctor you trust who knows about pediatric AIDS or is willing to enlist the help of specialists. There are other ways of assessing the child, such as blood cell counts and cultures, and the child's growth and

development should be watched closely. Again, your child will be more closely monitored and cared for if you feel comfortable about disclosing your HIV status.

Ironically, a woman who becomes pregnant and chooses to terminate that pregnancy will likewise have to face opposition by those who may oppose abortion in her family and community, and by health care providers or institutions where abortion is not made available. In a situation as volatile as this, it is important that you obtain accurate and supportive counselling, and then ultimately make your own decision.

The issue of informing medical personnel when seeking an abortion that you have tested HIV antibody positive is a difficult one. Facilities such as the Everywoman's Health Centre in Vancouver practice "universal precautions", which means that protective gloves are used and instruments are always disinfected. In this regard, they do not need to know the patient's HIV status. Counselling and care may be more uniquely supportive to a woman who informs the Clinic of her HIV antibody positive status, but it is up to the woman. At some hospitals, informing health care providers of your HIV status may mean risking the opposite, that is being treated in a demeaning way or being refused an abortion or care. If you do not wish to disclose your HIV status under those circumstances, check with the hospital to see whether they use universal precautions to ensure that both you and medical personnel are protected against infection.

In general, finding a counsellor or doctor that you trust is the best way to begin. Grief and feelings of loss may follow an abortion, and it is important that follow-up counselling be made available and that you have supportive family and friends to talk to if possible.

Is Pregnancy Risky?

Information presented at the last International AIDS Conference in 1992 seemed to indicate that pregnancy does not alter the course of AIDS. On the other hand, pregnancy in any woman alters some immune function, and other viral infections can be more serious during pregnancy. Generally, it is thought that the more healthy a woman is at the outset of her pregnancy, the less likely it is that the pregnancy will have a negative effect on her health. Likewise, it appears there is a greater chance that the baby will be HIV negative if the mother is healthy during pregnancy. But as with many other aspects of Women and AIDS, it is not known how to determine what a particular woman and child's health and HIV outcome will be.

A woman contemplating pregnancy should be aware of the state of her health, that is, whether she is experiencing symptoms or infections associated with AIDS/HIV. She should check the status of her immune system through blood tests and helper cell counts. She should be sure she understands the meaning of this information and its implications for her health.

If you decide to continue a pregnancy, your physician must be aware of your status. You will be watched more closely, and your care should take your HIV status into account. Ideally, the doctor should be knowledgeable about AIDS in pregnancy and babies, or at least in touch with

specialists who are. This is particularly important as the benefits of certain drug treatments which might be prescribed for the mother, especially those used to fight infections, must be weighed against potential damage to the foetus.

Early in your pregnancy, or possibly prior to becoming pregnant, your medical tests should include screening for infections such as hepatitis B, tuberculosis, and herpes, as well as routine screening for rubella (German measles), syphilis, gonorrhoea, and chlamydia. Your physician may also test you for infections such as cytomegalovirus (CMV) which occur more commonly in people with AIDS and HIV. These infections can have serious consequences on the developing foetus. Minor infections, such as vaginal yeast which is common in pregnancy, may also need to be monitored more closely. Any symptoms will need to be carefully investigated to determine their cause before any treatment is prescribed. As in any pregnancy, careful consideration must be given to the use of medication whether it is an ongoing treatment medication such as an anti-viral or a treatment for an acute temporary condition. In the best interests of both the woman and child this issue should be discussed at length before the woman becomes pregnant (if possible) and treatment implications examined closely.

Making a Decision About Pregnancy:

Deciding to become pregnant when you have AIDS/HIV is likely to be a very difficult decision, one that not everyone will understand. Because of the complexities involved, you will not only have to consider your reasons carefully, you will probably have to explain them to others. Motherhood may be tied to your sense of identity, and culturally, the importance of having a baby may outweigh the risk presented by AIDS/HIV. Pregnancy may provide the motivation needed to stay off drugs, or may bring a sense of purpose and future life. If you are healthy, you may feel that is a clear enough indication that your baby will be healthy too. Age may be a factor - a woman in her late 30's may feel she does not have the luxury of time to postpone this decision. Some women become pregnant before they have accepted, or even know, that they are HIV antibody positive. Others continue a pregnancy because they are unable to come to a clear decision in time to have an abortion.

No matter what your reasons are for becoming pregnant, you can lessen some of the pressure you will feel by taking good care of yourself and ensuring you receive good medical attention. The situation will be easier if you are living in a family setting which supports your pregnancy. It may also help you to contact other women with AIDS/HIV as a way of finding the extra support you will need prior to, during, and after the birth.

E. HAVING BABIES

Pregnancy when the mother has AIDS/HIV is not risk-free for the foetus. The presence of the virus appears to correspond with an increase in IUGR (intra-uterine growth retardation), and in premature delivery. A "dysmorphic" (abnormal) appearance has also been noted in some HIV-

infected babies. IUGR and early delivery also occur on a higher than average basis when the mother has been an IV drug user, and the abnormal facial features noted with HIV infection resemble those seen in babies born to alcoholic mothers. As research to date has not always taken possible overlap in causes into account, so it is not clear which fetal abnormalities are directly related to HIV infection.

Most children with AIDS contract the infection from their mothers via the placenta during pregnancy. Initially, it was thought that Caesarian sections (taking the baby out through abdominal surgery) would decrease the risk of infection to the baby, but studies have shown that natural birth has no relation to the baby's HIV status. If the labour is going well, there is no reason the delivery should not proceed normally through the vagina. You should ensure that all health care workers participating in the birth automatically use "universal precautions".

However when the mother has AIDS/HIV, certain procedures should be altered to more fully protect the child. For example, monitoring the baby's heartbeat during labour can be done externally (on the mother's belly) or internally (with an electrode attached to the baby's scalp inside the cervix). In the presence of HIV, it is a good idea to avoid the use of an internal monitor rather than chance contact between the mother's vaginal and cervical secretions and the baby's blood.

Caring for the Baby:

Breastfeeding has proven to be another unclear risk area. Generally, breastfeeding passes on some of the mother's immunity to the child, however there have been cases of the virus being passed to the child in the breast milk. You will have to weigh the risks and benefits carefully when deciding whether to breastfeed your baby. At this time it is felt that until more is known about breastfeeding and HIV transmission it is better not to breastfeed.

Given the possibility of HIV infection, you will need to meticulously care for the stump of the umbilicus, and you should not have the baby circumcised in order to avoid infection. As the child gets older, you will need to decide on immunizations individually. Immunizations containing live virus, such as oral polio, should be avoided until the baby is known to be HIV negative. Injectable dead virus polio vaccine can be used instead. The most recent guidelines should be used to determine whether the child should be given vaccines against measles, mumps and rubella (MMR) and Hemophilus influenza. Diphtheria, pertussis and tetanus (DPT) vaccine can be given at the routine times. In all cases, consult with your child's physician before deciding on immunization.

F. THE INFECTED CHILD

Children, like adults, may go for some years with no symptoms. It does seem that HIV infected children fall into two groups: one group becomes symptomatic quickly, while the other group

remains well for a much longer period of time. Also like adults, there is no absolute predictor of how on long that time will be. In the early stages of the illness, about 75% of infected children will show non-specific signs and symptoms such as fatigue, failure to thrive or weight loss, swollen lymph nodes, frequent respiratory infections, recurrent diarrhoea, and eczema-like rashes. As the syndrome progresses, the child may show nervous system manifestations such as a lag in development, an abnormal walk, or seizures. A chronic lung disorder called lymphoid interstitial pneumonitis (LIP) is unique to children with AIDS, and chronic respiratory symptoms may require oxygen and restricted activity. Kaposi's sarcoma (KS) is rare, but other opportunistic infections common to AIDS can occur.

In the Lower Mainland pediatric HIV/AIDS care is managed by the HIV Care Team at the British Columbia Children's Hospital. The Team operates under the direction of Dr. Jack Forbes: Department of Immunology. They may be reached by contacting the Hospital main switchboard.

Care of the Mother and Child:

The more supported you are in the care of your children, the more you will be able to protect your own health. Care of children presents a major problem for mothers with AIDS and HIV infection, especially those who are single parents or who have limited community and financial resources. It is not uncommon for mothers to leave their hospital beds in order to go home and care for their children.

It is also very difficult for a mother facing illness to determine who will care for her children if she dies when there is no obvious person to do so. It is a good idea to get accurate advice regarding whatever arrangements you wish to make with family members or friends about ongoing custody of your children to ensure that your decision is not challenged after your death.

When no arrangements have been made, the children are sent to the surviving parent or to foster care; in some cases, children are remanded to foster care when the mother becomes too ill to properly care for them. In this eventuality, take steps to ensure you have continued access to your children.

Housing for women with children can be another major problem. Some help and support is available in this area, but certainly more is needed. To investigate housing availability and subsidies, contact the Positive Women's Network, the Vancouver PWA Society, AIDS Vancouver or AIDS Vancouver Island. The Positive Women's Network, Native Health and Advocacy Access at the BC Coalition of People With Disabilities will also help you obtain full support under GAIN. Other opportunities for access to housing are provided by the B.C. Housing Society, McLaren housing Society, The Housing Society operated by PWA for B.C. Ministry of housing and local community co-operatives.

G. THE SPECIAL SITUATION OF WOMEN

Although the situation is beginning to change as more women become infected, women with AIDS and HIV infection face particular problems because of their minority status and different symptoms. For example, they may find they have less access to programs and facilities, or that programs are not designed with their needs in mind. All too frequently, medical personnel knowledgeable about AIDS are not familiar with gynaecological and obstetrical procedures which may be required, and those knowledgeable about obstetrics/gynaecology are not familiar with AIDS and HIV.

Drug therapies for AIDS/HIV-related infections are usually based on trials made up entirely of men and little is known of proper dosages or possible side-effects for women. Research studies with new drugs sometimes do not enrol women because their numbers are too low for "statistical significance". Women may not have the medical connections to hear about new research programs or childcare arrangements may make it too difficult to go to the many clinic visits required. The Advocacy Committee of the Vancouver PWA Society in cooperation with the Positive Women's Network can help women access medical trials, experimental treatments and information regarding local programs available. Assistance regarding access to childcare etc. can also be provided.

Nonetheless, women with AIDS and HIV infection are beginning to reach out and access the services they need. Support groups exist through the Positive Women's Network. The Network is located at 1107 Seymour Street in downtown Vancouver. Their telephone number is 893-2200 and fax number is 893-2251. Call ahead before dropping in, as their hours may vary. You can also get information and support through the Vancouver PWA Society which has active women members, the Needle Exchange, AIDS Vancouver and AIDS Vancouver Island.

CHAPTER NINE: CARING FOR SOMEONE WITH AIDS / HIV

A. WHAT TO DO AS A CAREGIVER

If you are the lover, close friend or family of someone living with AIDS/HIV, you may be involved in caring for that person in the future. As a caregiver, you will have an extremely important role to play. As a lover, friend or family member, you will also face challenges.

There are no hard and fast rules on what to expect, and particularly if you have never faced this situation before, you may feel alone and confused at times. Try to talk with someone else who has been in this position, whether a friend or someone you contact through one of the AIDS organizations. Their experience may not be exactly the same as yours, but they will understand and support what you are going through. You will also find good allies in your loved one's medical care team and other close friends.

If there is a single principle to keep in mind, it is "It is up to the person living with AIDS/HIV to decide what kind of care they require". Sorting out when your help is needed and when it's not is something you will have to do by talking with your loved one - and by listening to what they want. When faced with potentially fatal illness in someone they love, people tend to become overprotective, oversolicitous in trying to meet their loved one's every anticipated need. This is an impossible task, one guaranteed to drive you and your loved one crazy. Relax. They will tell you what they need when they need it, if indeed they need anything at all. When in doubt, ask. And then respect the answer.

After receiving a positive HIV antibody test result, the first things your loved one will need from you are understanding, love and respect. With no choice and frequently little warning, their life has been turned upside down and they are likely to feel very vulnerable, particularly for the first while. Much as you may want to "rescue" the person you love and try to make them feel better, you will not be able to do so. They will have to find their own path in dealing with the challenge of AIDS. What you can do is to understand that this will be a difficult and uneven process, and that your loved one may react to the pressure in seemingly unusual ways. All they really need you to do at that point is to acknowledge their feelings and to stay with them as they come to terms with the reality of their life. Do be alert for depression that does not seem to lift, or other signs that your loved one may need some professional help or guidance.

Once your loved one is past the initial shock, life may settle down again for some time as the virus moves very slowly and years can pass before any symptoms become evident. The challenge may have changed your loved one markedly, or seemingly not at all. That is their choice and their path. Again, all you can do is respect whatever decisions they make and offer whatever support you can as a friend. Don't be afraid to continue a sexual relationship (see Chapter VI); there are many pleasurable ways to be close without putting your loved one or yourself in any danger. Also try not to treat your loved one as a fragile invalid. They will probably notice no changes for some time. People are still alive and thriving ten years after an HIV antibody positive diagnosis.

There are certain ways you can help a loved one living with AIDS/HIV. Encourage them to eat properly, get enough sleep, and generally take care of themselves. Be alert to excess use of alcohol or other substances which are likely to damage the immune system. Your loved one may ignore all advice, but gentle reminders from someone close may help. You can also help keep their life interesting by taking them to a movie, having friends for dinner, joining with them in whatever they like to do. By the same token, respect your loved one's need to sometimes be alone. You can also help by watching for early signs of AIDS/HIV-related infections. The earlier treatment is given, the more likely it is to succeed.

When illness does occur, let your loved one take the lead in deciding what to do. They may feel the need to get everything settled at once, from a living will to funeral arrangements. If this is their choice, then support it and help the process. But make sure you are doing this for their comfort, not yours nor that of some other member of the family. It is likely that your loved one will want to talk about their illness, sometimes at great depth, and they may begin discussing their death. This may be difficult at first, but the whole process will be easier if both of you can discuss and consider what is occurring. On the other hand, if they don't wish to talk, respect that choice.

You will find that sharing this time with your loved one can bring you great intimacy and great joy. Your sense of humour will help you both a great deal - a good laugh is sometimes the best treatment around. You will also find your loved one becoming angry and frustrated, sometimes for no apparent reason. That anger could be quite justifiable, particularly if they feel they are beginning to lose control over their life and their decisions. Hear the anger. Don't take it personally. And support their continued independence in any way you can.

If your loved one becomes very ill, you will have certain very practical matters to consider. Your loved one should now be gently reminded to be sure all legal documents are up to date, that their will is clear, that they have a living will and medical power of attorney if they want one, and that their wishes on medical care are clear. This may be difficult if they are not prepared to deal with these matters, but the situation will be much easier for everyone if their wishes are known.

Once a medical power of attorney has been designated, that person, in consultation with the person with AIDS, should put together a 'care team'. A 'care team' is a group of friends, family, etc. who will undertake to ensure the person with AIDS has 24 hour care and support for as long as is necessary. This team can provide support while the person is in hospital, or can provide very practical care, in conjunction with medical personnel, which enables the person to stay at home. It is important to realize that this team must provide medical support, must ensure medicines are taken, deal with straight practical matters that will keep the patient as comfortable and cared for as possible. To do this, the team captain may need to consult with medical personnel on a regular basis. This includes talking with the patient's physician, social worker, and other care personnel. Good advice can also be obtained from the Palliative Care Unit at St. Paul's Hospital in Vancouver. They are helpful and knowledgeable - the best.

Team members will also provide the patient with emotional support. This means listening, talking with the patient when they wish, just being there when they need to be silent. When someone is ill, they don't always need a lot of fussing. It may be sufficient and very welcome if you just sit there quietly and hold their hand. Support your loved one keeping control of this as well as every other aspect of their care.

One of the most difficult decisions for your loved one will be whether to go into hospital or to stay at home in the face of serious illness. If homecare is to be a valid option, you must ensure that the level of care will be comprehensive and consistent. You do your loved one no favour by keeping them at home if they do not receive adequate care. By the same token, your loved one will probably need support and some advocacy to ensure that they receive personal attention in the hospital. Most hospitals welcome partners, close friends and family in cases of serious illness, but you would be wise to check with the hospital ahead of time to be sure. Should your loved one opt to enter hospital, they will need to decide with their doctor whether to go to a treatment floor, or whether to go into Palliative Care, where the consideration is the comfort rather than the cure of the patient. Support your loved one in whatever choice they make.

Finally, take care of yourself and respect the fact that some of the caregiving will make difficult demands on you. Try to maintain a social life, see other friends, reach out for support when you need it. If you feel you need counselling, any of the AIDS organizations can refer you to a knowledgeable counsellor. Be positive, cheerful, understanding, and value the time you and your loved one have with each other.

B. "I HAVE AIDS" by David Morgan

The following article was written by Vancouver PWA Society member David Morgan for the January 1989 edition of *The Canadian Nurse*, and is reprinted with their kind permission. David Morgan died from AIDS-related causes in October, 1989.

I attended many workshops at the Canadian AIDS Conference in Toronto last May. But by the end of the Conference I was exasperated. I thought, "I feel invisible - you've talked about ethics, compulsory testing, funding, education and contagion, but nothing that's relevant to me as a person with AIDS." What I care about are the unreserved release of experimental drugs for those of us with catastrophic fatal illnesses; the development of good hospice care across Canada; the legalization of the living will; and, in the future, legalized euthanasia. I'd also like to see funding for persons with AIDS groups. I hope this article provides insight into what it is like to be gay and to have AIDS, and why my personal rights and freedoms are so important to me.

Sometimes it's hard for me, surrounded as I am by gay people and by health care professionals who take my being gay for granted, to remember that many Canadians do not realize they know a gay person. Yet at all times and in all places, the number of gays is about six percent of the population - about one in 20 people.

Although AIDS may not be a gay disease, most North Americans who have AIDS are gay. For some, that is significant, for others immaterial. I repressed my sexuality until I was 31, along with my other emotions and a willingness to let others come emotionally close. A woman finally released my sexuality, and a few months later I had sex with a man. I woke up the following morning feeling born again and whole, for the first time in my life. From the start, I decided not to compartmentalize my life; I knew the cost of repression. It was the best of decisions, and one that has brought surprisingly few negative reactions.

I have treated having AIDS in the same manner. I am not ashamed of being gay or of having AIDS. When I contracted the disease I thought I had as much chance of getting it as the heterosexual woman living in Calgary today. I was an innocent. Now, none of us can afford to be innocent, or squeamish about using phrases such as "mutual masturbation". The costs are too high.

Each of us with AIDS has a unique story. My friend Kevin has had seven bouts of pneumocystis carinii pneumonia and is still alive after three years. My friend Randy walked into hospital and was dead in the intensive care unit 24 days later. Some AIDS patients think they can beat the odds and live a full life span. Others, like me, know we are likely to be dead within a year, but believe it is most important to live fully as long as we are alive.

My story starts in May of 1983, when I participated in the Vancouver Lymphadenopathy-AIDS Study. My doctor told me I was HIV positive. No one offered counselling. Emotionally numb, I realized I couldn't do anything with the information anyway.

Shortly thereafter I embarked on a three-month solo motorcycle camping trip across America to New York, up to Ottawa and back to Vancouver via the Yellowhead Highway. Three weeks into the trip, in the middle of Utah, I caught the flu. Scared and alone in my tent, I didn't know whether it was "just the flu" or the beginning of a terminal opportunistic infection. Since then, I've learned to take a deep breath and say, "C'est la vie".

But *c'est la vie* is too flippant. The stamina of people with AIDS is amazing. Rereading my diary for the spring of 1986, I think, "I survived that?!" In late 1985 my friend Ted, who had been sick with AIDS for a couple of years, died after being bedridden for months. January 10th, 1986, I came down with a bout of flu, which I never felt I got over completely. On January 30th, 60-year-old Howard died of AIDS, leaving a lover of fifteen years to mourn his death.

On February 4th, my crazy, neurotic, demented friend Dick was taken to hospital by the police. We brought him out on a day pass on the 5th for Howard's funeral. He wouldn't go back to the hospital until he had received a refund from the grocery store for his dead daffodils. They (thank God) refunded the money.

Soon after arriving back at the hospital, at about 5:00 in the afternoon, Dick sat in a wheelchair, wheeled out of his room and with a big smile on his face said, "I'm ready for my hemorrhoid operation." When told, "I don't think you have one planned, Dick," he pounded his fist

repeatedly on the charr, yelling, "I want my hemorrhoid operation!" Some of the nursing staff suggested he might like a Haldol instead, but Dick was deranged, not stupid, and didn't fall for that. Instead, he sat by the pay phone, calling doctors until midnight.

Before Dick was hospitalized, he had driven his friends crazy with long incoherent telephone calls and demands for help. We all felt individually responsible for his well-being and guilty that we couldn't meet the demands. I learned the value of support groups. I called a Saturday meeting of his friends, his doctor, members of the denim and leather fraternity to which Dick and I belonged, a representative from AIDS Vancouver and an AIDS Vancouver homemaker.

Everyone arrived promptly for hot coffee, buns and strategy planning. I began by saying, "We are all going to hold hands and scream out our frustrations." The results of the meeting were wonderful. Sharing our care for Dick, we scheduled things so Dick had someone with him at all times. When he died at 1:30 in the morning on March 4th, Dick was not alone. Dick's death was a good death. Success isn't only a cure.

As each of his friends spent time with him that last month, Dick told us his "unfinished business" with us. Most of us never knew what he was talking about; it didn't matter. Dick died content and at peace with himself. I felt sorry for his 60-year-old father. He flew to Vancouver from Toronto to discover not only that his son was gay, but that Dick's death was imminent. Only shock kept the poor man from cracking. The memorial service was a blessing for him, as he met and spoke with Dick's friends and acquaintances. All were pleasant, kind, normal people - not a queer pervert in sight. (If you have never knowingly met a gay person, how are you to realize we are normal? I believe all gays and lesbians need to let their families know their sexual orientation, for better or worse.)

Dick's funeral was March 11th. It was particularly draining for me, for I had been admitted to St. Paul's Hospital the day before Dick's death. I had a day pass to attend the funeral. When I returned to the hospital I was met by Tammy, ostensibly a student nurse, but, to me, an angel in disguise. We stood in the hallway and she just listened, really listened, as I told her about my illness, the illnesses and deaths of Ted, Howard and Dick, and their cumulative effect on me. I bless Tammy every time I think of her. After I had talked by heart out, she found me cranberry juice and ginger ale - the comforting balm of hospitals - and a private bathtub in which I could cry and pound my fists.

On the 21st of March I had an open lung biopsy, followed by ten weeks of pain and discomfort. The doctors claimed I didn't have AIDS. I didn't believe them. They suggested I might be experiencing an allergic reaction to pigeon droppings or perhaps my motorcycle leathers. I even swapped apartments with a friend from April 19th to May 19th, trying to eliminate possible environmental factors. It was the worst time of my life: no diagnosis; sore chest; fevers during the day; drenching sweating at night; malaise; nausea; and deep depression. Although I remained socially active, life was not worth living. Finally, I set a date for my suicide. (I still believe it would have been a rational suicide.)

In the nick of time, my doctors prescribed prednisone. I could eat; the fevers and night sweats ended; I cared about my friends again. I returned to my own apartment, and all seemed right with the world.... until July 28th, when, panting and blue-faced, I nearly collapsed into my respiratory specialist's office. It was pneumocystis carinii pneumonia. I had AIDS.

With Dick I had shared the frustrating experience of being extremely sick but unable to get a diagnosis. Without diagnosis, there's no treatment; friends tend to think you are just being neurotic. Ironically, a diagnosis of AIDS can bring a small measure of relief, for at least it brings your friends' support. The other benefit of a diagnosis is Employment Long Term Disability insurance. Having this income has been critical to my self-reliance and happiness. I am also fortunate to have had a boss who put up with an unreliable, easily fatigued employee, before I became too sick to work at all.

Knowing what I had, and knowing the pneumocystis carinii pneumonia was treatable, was a relief. "Treat me so I can enjoy the summer," I thought.

A poignant moment occurred when I arrived in my hospital room and my friend Paul wordlessly put his arms around me. I burst into tears. "Paul, I am not afraid of dying. I am afraid of being sick, and I'm afraid of becoming incontinent and demented." This is still my worst fear.

During 14 days of intravenous Septra, then 12 days of intravenous pentamidine, my temperature chart looked like the peaks of the Rockies. I remember asking my respiratory specialist, "Should I work on my resume or my will?" Another day, during the shakes and chills stage of the daily fever, I was being wheeled down the hall for a bronchoscopy. Looking at my trembling hands, I said through chattering teeth, "I know what I'm good for - a bartender shaking up cocktails." It was close to a month after my diagnosis before I finally shuffled out to enjoy the summer sun.

Other amusing incidents occurred. On one occasion, chatting to friends, I said in my inimitably loud voice, "I'm as kinky as a pubic hair." A starched white hat walking by stopped abruptly in the doorway. The smiling face glancing into the room said, "You're what?!", then disappeared.

Another time a friend visited to give me a massage. If you don't have a lover, being touched is rare. After he finished, I asked him to lie beside me for a few minutes (he was dressed, I was naked). Maria walked in; Maria walked out. Next day I was able to tell her we hadn't been doing anything sexual and I hadn't intended to offend her. She just said, "Next time, put a 'do not disturb' sign on the door." Point taken.

During my stage of high temperatures, I was amazed by my physical and emotional weakness. For a while, I thought it was just a lack of mental resolve, but a friend said he hadn't been able to get out of bed even though he was in pain with a "bursting" bladder. At times like these, a friendly, helping hand is a blessing. The nursing staff were excellent and caring. I was never made to feel I was troublesome if I rang for a ginger ale. (After an intravenous pentamidine treatment most liquids make your mouth taste like a mixture of tarnished silver and grapefruit

juice. Something about the way ginger ale foams out of a styrofoam cup makes it the most palatable beverage.)

AIDS patients at St. Paul's are luckier, I would guess, than almost anywhere else. Ann, the nurse in charge of infection control, is an effective, friendly person. Having set up adequate precautions, she has trained her staff to be careful rather than paranoid. Except for sending one lunch with plastic cutlery, the staff at St. Paul's never made me feel like a leper or any less of a person because I am gay. While in hospital I sometimes asked myself, "Am I being treated as I would be if I were a heterosexual recovering from appendicitis?" The answer was always yes.

When I left St. Paul's, I joined the Vancouver Persons with AIDS Coalition. Two other members were recently admitted to St. Paul's. Terry, a big, strapping man with an Australian heritage, is gentler than a teddy bear. His lover Rick was always frail. He had tuberculosis and Kaposi's sarcoma, as well as aches, pains and feet so sore he wheeled about town on a powered tricycle. He was as thin, sarcastic and witty as Terry is big, gentle and soft spoken. Their love for and devotion to each other were a delight to see. It made my heart sing when I went to visit them in hospital and found they had been put together in a two-bed room. How many other hospitals would have shown that sort of compassion? (Rick has since died.)

There are other special considerations for AIDS patients who are gay. When first admitted, I spoke to the head nurse and requested that my friends be treated as biological family in regard to access to my medical information. I have an 83-year-old mother, and a sister who lives in Toronto, but it is my friends who are my emotional support and my advocates.

Family needs to be defined broadly. A release form should be presented to patients to indicate who can receive what medical information. I think it essential all patients be asked if they have prepared a will, an enduring medical power of attorney and a "living will." I know a number of horror stories of a person dying of AIDS without a will. The biological family, having ignored the person for years, took over funeral arrangements and property, leaving the lover of long standing with nothing - not even the dignity of participating in the memorial service.

It has now been over two years since my diagnosis of AIDS. Every illness is frightening, as I never know whether it is a passing sickness, a treatable infection or the beginning of the end. A cough persisted for a month only to disappear; periods of night sweats have come and gone; a white tongue and disappearing fingernails are caused by candidiasis I cannot control; periods of malaise are the most emotionally debilitating; blackouts occur; and a tender scalp, of which the focus shifts around my head, makes wearing my motorcycle helmet somewhat problematic.

I am not afraid of death. I do not believe in heaven, hell or reincarnation. I expect to become a subatomic elemental particle in a wonderful universe. Since the diagnosis, I have believed the length of my life is of less importance than how I live. Having dealt with death, I can get on with the joys, quirks and pains of living. I've enjoyed a full life. I've scuba-dived, skydived, hitchhiked through Europe, crewed a leaking 120-foot boat to Costa Rica, been politically active, enjoyed my job as an audiovisual specialist, explored my sexuality and had two lovers who are

still good friends. My only regret is not being in the middle of an "old-shoe" relationship now. Currently, I'm enjoying my free time; riding my motorcycle, taking photographs, visiting friends, eating out and going to movies. Not bad for a sickie.

A nurse recently asked what she could do for me. "Two things," I replied. First, allow yourself to be afraid. Gays, lesbians and AIDS are frightening until the strangeness passes. When I told my parents I was gay, Dad said, "Tell me about it so I can understand." But a month and one book later he felt no better. He never let himself feel afraid, so he never did understand. He died last summer, feeling guilty and pitying me. Mom's initial response was "I don't want to hear about this." Yet, over the next year, clippings on gay issues appeared on her refrigerator. She now says, "I don't know why there's all the fuss about being gay; relationships are no different between two men, two women or a man and a woman." Yea, Mom!

The second thing you can do is help me lobby for the issues that affect me: the unreserved release of experimental drugs for those of us with catastrophic fatal illnesses; the development of good hospice care across Canada; the legalization of the living will; legalized euthanasia; and funding for persons with AIDS groups. As nurses, you are part of a large, important organization, an organization that can have a tremendous impact in defeating this disease.

Finally, I hope that should you find yourself nursing one of us with AIDS, you gain satisfaction not by keeping the patient alive, but by facilitating the patient's quality of life. Help us maintain our personal rights and freedoms and our sense of self-worth. I hope you gain satisfaction from coming to know those of us with AIDS. Please, sit on the edge of the bed and give us a hug if you feel like it. I'd like that.

CHAPTER TEN: MAKING SENSE OF LIFE WITH AIDS / HIV

A. AIDS AND SPIRITUALITY

As much as AIDS/HIV is a physical challenge, it is an emotional challenge and a spiritual challenge. While your body is challenged to cope with illness, your emotions are challenged by thoughts of death and loss of control, and you are spiritually challenged to try to make some sense of it all. Making sense of AIDS is a tall order.

And yet it is common for people living with AIDS/HIV to find renewed purpose and deeper values as they come to terms with this syndrome. In fact, it is becoming evident that those who take a positive approach to maintaining control of their health and their lives stay healthier far longer than those who simply give up. Most medical personnel accept that there is a relationship between the body and the mind, one evidenced by the mind's contribution to physical maladies like ulcers. Circumstantial evidence is beginning to indicate that the mind may also affect the immune system, for good and for ill.

A number of programs based on the 'mind-body' connection have been developed over the past few years to help people with AIDS and HIV infection use their mental energy to maintain their physical health. Some people have found these programs to be very successful; others have found the same programs a waste of time. The response seems to be as individual as the participant. If you decide to undertake this kind of program, be a cautious consumer. You can spend a great deal of money going to workshop after workshop or you may find something that works for you at very little cost. Talk with other PWA/HIVs and find out what has worked for them before making up your mind.

One of the key benefits to undertaking this type of approach may be a renewed connection to the spiritual aspects of your life. If you are so inclined, you can find religious support to help you in that search. Not all churches understand or accept people living with AIDS and HIV infection, but certain individuals within most religious affiliations are open and helpful. The Vancouver PWA Society and other AIDS organizations should be able to give you the names of sympathetic pastors. If you find you have consulted someone who does not understand your problems or blames you for your condition, find someone else.

Talking with other PWA/HIVs is also a valuable way to find spiritual support. Sharing with others asking the same questions can sometimes help you find your own answers. You can also consult the libraries of most AIDS groups, which will contain books dealing with the spiritual aspects of living with AIDS and HIV.

B. AIDS AND MEDITATION

There is no single answer to finding peace, acceptance and spiritual happiness. However, one practice that has worked well for a number of PWAs is meditation. The following article was written by four members of the Vipassana meditation group in Vancouver, a meditation group

for people living with AIDS and HIV, and was published in the Spring 1989 issue of the Karuna Meditation Journal. Since publication of this article, all four have died of AIDS-related causes:

"MEDITATION and AIDS"

Kristin Penn offers a meditation class in Vancouver for people with AIDS and HIV, which she calls "Living in Each Moment". This insight meditation class is also open to friends and supporters. The format of the group includes discussion of the basic Buddhist principles which form the foundation of the practice, and instructions in sitting, lying and walking meditation. The class is followed by tea and informal conversation. Here, four people with AIDS/HIV talk about how they have found the meditation to be useful for them.

Sean Stephenson:

I was diagnosed with Kaposi's Sarcoma, (a rare form of cancer), and PCP (viral pneumonia) in September, 1987. Before being diagnosed with AIDS, I had an extremely stressful job and was chronically depressed. I actually remember saying to myself one night before falling asleep, "I wish that I had AIDS", because it would be a way of filling the terrible void I felt within myself, a way of conveniently ending it all.

Faced with the prospect of dying, however, I gradually found myself filled with the longing to live, filled with the desire to discover who I was.

Slowly, through daily meditation, I am discovering that no matter what the constantly changing external and internal circumstances are now or have been in my lifetime, deeper than those circumstances is an abiding sense of happiness and peace, of security and safety. I feel a wellspring of love and wellbeing that I have truly never felt before in my life. Strange how our backs have to be completely up against the wall before we realize that we have to change, and before we fully appreciate what we already have.

The popular media leads all of us to believe that AIDS is a fatal disease and it is so easy to buy into that fear. I may indeed die from this disease. I have seen my friends drop like tenpins all around me. It is not death that I fear though, but the pain that might come before death. But I also know that when we project the fear of pain into the future, we don't think that we have the capacity to handle it. When it is right here, we are usually able to bear it.

We speak of the law of impermanence in our meditation class and death as simply a transition, a part of a process wherein we arise, we flourish, we diminish and we disappear. Had I not had to face AIDS, I might not have had the opportunity to prepare for death. In that sense this illness has been an opportunity, a gift.

Meditation forms my first waking moments and my last moments before sleep. It is something I can do anywhere and everywhere. It still does not come easily to me. But I see my meditation practice as my precious jewel, to be cherished and nurtured.

Jerome Aspelung:

When I was diagnosed with AIDS about a year ago, initially I was upset and depressed, but I seemed to get over that fairly quickly. Then for a while I was ridiculously happy. I had incredible friends who were very supportive. I felt I had so much to be grateful for. I was also very happy in my relationship for a while. But getting AIDS opened up a whole bag of issues for me that I couldn't avoid any more, mainly to do with my sense of self-esteem. I had been overly compromising in my relationship, but getting ill shattered some of that acquiescence because I now didn't know how much time I had left in which to live my life. This was the obvious cue to get on with living as enjoyably as I could.

When I first came to the meditation group, things started changing quite dramatically. I was astonished by how accepting the group was. The group, the practice, the whole approach of the meditation was to say, "You're perfectly okay the way you are." This was also true in the Tai Chi class I started around the same time. I was suddenly in a situation where I was not being criticized for what I was doing or how I was doing it or for who I am. I began to realize that I am a full, multi-dimensional person and was reminded of all the things I wanted to be and do that I had suppressed.

Bill Ives:

I joined the meditation group because I was intrigued by the idea of doing something meditative to help me become more calm. I had no idea about all the other things that would happen because of the meditation. I also wanted the social contact with other people that the group would provide. As well, I had been interested in Buddhism as a religion or a way of life for a long time.

I like the discussions that we have in the group on the Buddhist principles of the practice. This intellectual content adds a dimension to the group that you don't get in a general support group. I like the moderation, sensibility, and rationality of Buddhism. It's an easy philosophy, in that you don't have to wedge yourself into a mould in order to practice it. The lack of dogma is very attractive because my beliefs and ideas come from the actual doing of the meditation and our discussions based on the practice itself. I think that had the group been Christian meditation I wouldn't have bothered coming, although ironically I have discovered that there are many things that are almost exactly parallel with Christian practice.

I have been doing the meditation at least once a day for the last eight months and it pulls me beyond my usual concerns and worries. My physical state of frequent high fever and the drugs I am on are not conducive to calm. I find myself worrying about many different things. Often

as I'm doing some activity like reading a book or watching TV, I will suddenly realize that I have been stewing about some issue that isn't a part of the here and now. Or when I bring my attention to my body I might find that I'm sitting with my feet very tense, the only part touching the ground are my toes.

I have had the importance of relaxing drilled into me by so many other techniques and practices or therapies, but I've found that the insight meditation has worked best for me to become more aware of myself and everything around me. Sometimes it's just a valiant attempt and I still find myself wound up like a spring and feeling upset or unhappy. It's not a cure-all, but with a lot of determined practice I know I could become a much less "hyper" person than I've been in my life.

Richard Wright:

I was diagnosed in December 1987 and during the two months after the diagnosis and before joining the meditation group, I had nothing but grim news from my doctor. I suppose that it was partly curiosity, but mostly desperation that led me to the meditation group. That was a year ago and I have been meditating regularly ever since.

The year has been a tremendous opportunity to gain some understanding of myself and to make changes which I hadn't done because I felt I didn't have the time in my busy life. I see that now is the time to enjoy life. Just the fact of having the disease is very much bringing me into the present, but the meditation practice is giving me a nudge in that direction, too. I'm not living anymore on plans and hopes and dreams. I'm enjoying everyday things more, my relationship with David, my friends, my physical surroundings. I've gotten involved with a music group and an art group, doing activities that I've always liked but hadn't actively pursued for a while. Despite having a life-threatening disease, I'm not thinking about death and dying; I'm really thinking about living now.

This may sound a little lofty, but I feel like what is most important for me right now is learning to love. I'm still learning what that means, but I know that to love and forgive myself and the people around me is the most important task for me right now. Everything flows from that.

I always thought that I wanted to leave the world a better place than I found it, but I thought that meant building something or doing a work of art. But I realize now that if you can introduce some love into the world, what better thing can there be to leave? I may never get to build a bridge or create a work of art, but I can spread some love. There's a lot of time for that.

C. EMPOWERMENT:

The following article describes the principle of empowerment which has been the sustaining philosophy of the Vancouver Persons With AIDS Society. The article was originally published as part of an Evaluation of the Society's Programs:

EMPOWERMENT OF MEMBERS AND THE SOCIETY:

"First and foremost, the concept that has shaped the PWA Coalition is empowerment - taking charge of your life. If you see yourself as a victim, that's a short cut to death."

Kevin Brown

One of the major challenges for persons with AIDS/HIV is the loss of control they face over many aspects of their lives. Bodies that were healthy become prey to unexpected and frequently unknown infections. Because of illness, jobs are lost and income plummets. This in turn leads to necessary, but difficult, changes in housing and lifestyle. Medical information can be conflicting or nonexistent, leading to confusion, fear and frustration about maintaining health and staying alive. On their own, people frequently do not know where to turn.

The key concept by which the Society defines itself is empowerment, the belief that members must have the information and support necessary to maintain control of their lives and a sense of personal power. The commitment to this principle has shaped the Society's priorities, defined its purposes and provided the impetus for its growth.

Empowerment of members takes a number of different forms - some of them very personal; some of them broader and more general. On a personal level, it could be said that all programs and activities contribute in some way or another to helping members take charge of their lives. Programs like the Newsletter and the Library provide up to date medical and treatment material, giving people information which enables them to become equal partners in their medical care. Peer Counselling, the Living Room Lounge, Drop-ins and Social Events provide support and the opportunity to share experiences, reinforcing the knowledge that members are not alone in dealing with AIDS and HIV. Programs such as Blood Testing, Housing Referrals, and Volunteer Meals provide more practical support, helping members to achieve physical stability and reduce stress in their lives.

The advocacy function of the Society fills a special role in the process of empowerment, providing a mechanism to promote the rights of members. The work of the Advocacy Committee frequently includes helping members deal with specific situations, providing advice when requested and active lobbying when necessary. This function also works on a more comprehensive level to promote the empowerment of members to the media and at all levels of government policy.

The advocacy role of the Society includes assisting members in accessing services, as well as documenting complaints of AIDS/HIV-related discrimination; maintaining the 'public image' of the Society, through advertising, media interviews and relations, the Speakers' Bureau; external relations with other local, national and international organizations; and political activities and contacts with politicians at all levels. On a daily basis, the Advocacy Committee works as intermediary, or ombudsman, for members having difficulties accessing benefits, or drugs, or who are experiencing discrimination resulting from their real or perceived health conditions.

It is impossible to talk about the conventional response to the challenge presented by AIDS/HIV without emphasizing the crucial role being played by community based self-help self-care organizations. While governments and their agencies were slow to react to the needs of Persons With AIDS and HIV, the people directly affected by this syndrome were not. Throughout North America, persons affected by AIDS/HIV have responded with compassion and organization, providing much-needed services and support to others like themselves.

Over the years these groups have also worked increasingly with each other to 'advocate' for the rights and empowerment of all persons with the virus. The Vancouver PWA Society has been in the forefront of this movement in Canada. This level of empowerment has included the intensive lobbying which led to the release of AZT in Canada under the Emergency Drug Release Program, the legal battle with the Government of British Columbia to obtain full financial coverage for AZT under the Pharmacare program, active consultation on the formulation of the National AIDS Strategy, and current consultation on the B.C. Provincial AIDS Strategy.

Certain principles promoted by the Society since its inception have become accepted standards of government policy. The recently announced National AIDS Strategy clearly articulated the principle that Persons With AIDS/HIV be consulted on all issues that affect their lives. This echoes Kevin Brown's pronouncement that persons with AIDS are not the problem; they are part of the solution.

The Society has equally promoted the view that persons with AIDS/HIV must be equal partners in their medical care. This philosophy, echoed by other groups across the country, has resulted in innovations such as the establishment at the University of Toronto of a national Treatment Information System for AIDS/HIV, a system whereby the most current and reliable information regarding the treatment of AIDS/HIV will be made available to physicians, patients and community groups across the country. This treatment information system is unprecedented anywhere in the world and may prove the genesis of a system for treatments on other diseases.

The importance of empowerment as a principal mandate of the Society, and the Society's success in fulfilling that mandate, were both fully supported during the Evaluation. Respondents to the questionnaire spoke of the Society as "a place to be fulfilled", saying that it gives them, "a feeling of being useful"; "a place to channel my energy", "the tools to be part of the solution"; "direction towards self-help"; "a place I can go to be with people who understand"; "information to be a full partner in medical care"; and "hope, companionship and strength".

Evidence is beginning to show that the attitude of someone with AIDS/HIV toward their health can be as important as many of the self-care steps they take. These attitudes include:

- Taking personal responsibility for health and treating the doctor as a collaborator.
- Being assertive and having the ability to say "no".
- Being able to nurture themselves.
- Being sensitive to their bodies, and to their psychological needs.
- Being able to communicate openly about their needs, including their illness.

The example of the Society has proven that members act in keeping with this evidence and feel that the Society is contributing to giving them a new lease on life. As one respondent commented in the questionnaire, "AIDS = Accelerated Inner Development Syndrome".

D. LIVING YOUR OWN LIFE

Now that you have at least the beginning of the information you will need on living with AIDS/HIV, you can begin to make decisions on the path you wish your life to take according to your own priorities and values. It has been said that knowledge is power, and you will need the power of knowledge if you are to remain a partner in your medical care and economic decisions. Your life has changed. Now you must decide where to go from here.

Take heart. AIDS is a challenge, but knowledge about the syndrome is constantly increasing. People are living longer and longer as opportunistic infections are routinely treated. Early, knowledgeable medical care seems to be the key to this success, and many opportunistic infections such as PCP can be prevented through the use of prophylactic drugs. Within the not too distant future, we hope that AIDS will be a chronic, manageable condition. In the meantime, support is available. There are good doctors who know a great deal about treating AIDS-related infections. A number of complimentary therapies are also showing very promising results. And new books and articles are constantly being issued, reporting results of the latest research.

Community groups are also there to support you. The Vancouver PWA Society can provide peer counselling, the latest information on treatments, help with fighting for your rights, very practical support to help make your life a little better, and a place where you can meet others dealing with issues like yours. The Society has members throughout the province, male and female, gay, straight, bisexual, single and married. If you are a woman, you can contact the Positive Women's Network. On the Island, you can reach a PWA support group through AIDS Vancouver Island or you can contact Island members through the Vancouver PWA Society.

If you need a buddy, counselling or extraordinary assistance, you can contact AIDS Vancouver or AIDS Vancouver Island. The Street Project and the Needle Exchange offer a wide variety of services if you are street-involved or a substance user. If you have an aboriginal background, you can contact the Vancouver Native Health Society and the Vancouver PWA Society. If you

have AIDS/HIV and hemophilia, you can find support and information through the BC Chapter of the Canadian Hemophilia Society.

It has been shown that PWA/HIVs who take positive steps to maintain control of their lives and take responsibility for their health live longer and fare better. What you do with your life is up to you. What we can do is be there to support what you choose.