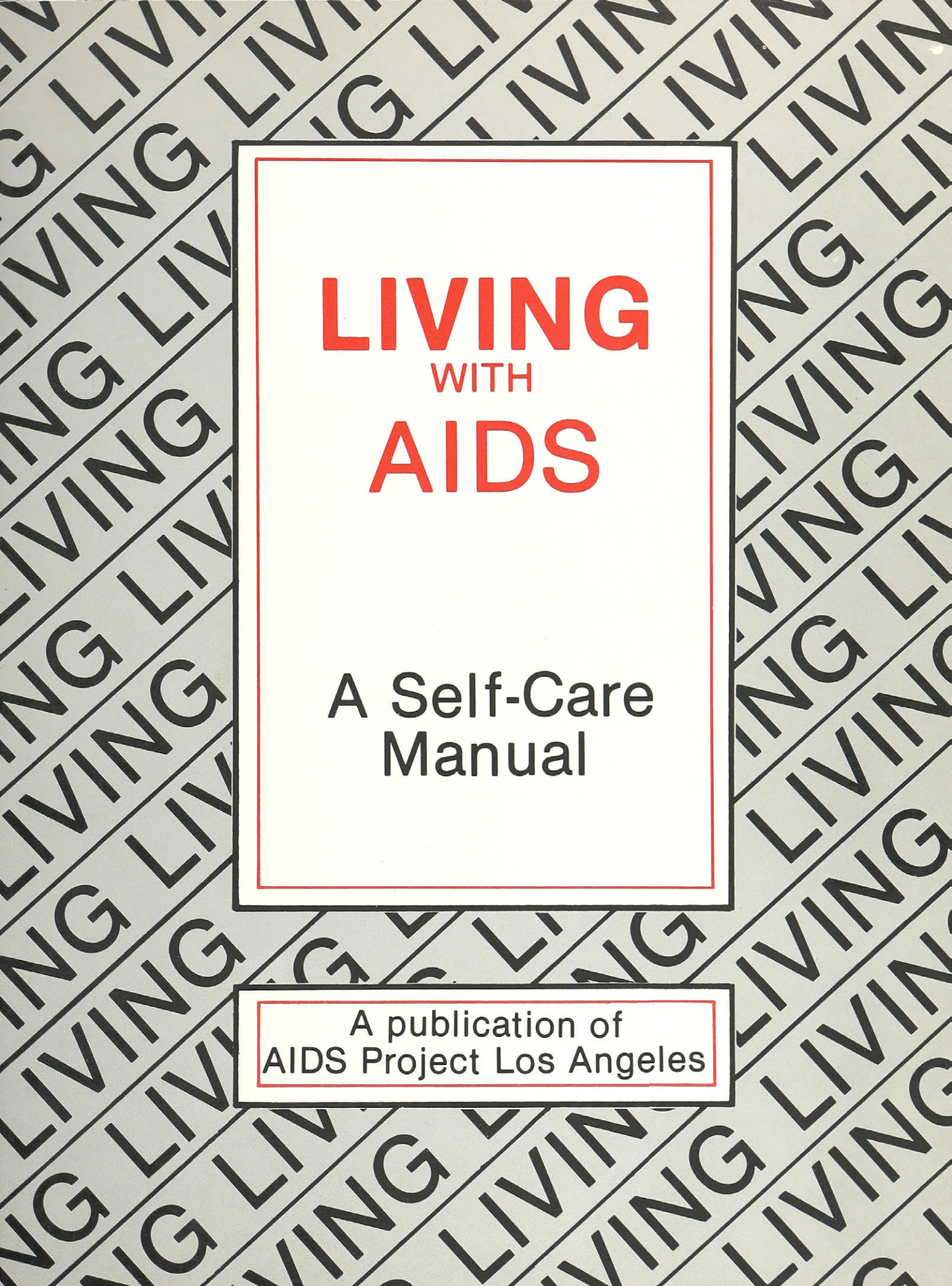




# **LIVING** WITH **AIDS**

A Self-Care  
Manual

A publication of  
AIDS Project Los Angeles

# **LIVING WITH AIDS**

## **A SELF-CARE MANUAL**

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## **DEDICATION**

This Self-Care guide is dedicated to the People with AIDS and related illnesses who have taught us so much about living with a life-threatening situation. Their hope helps us through this frustrating era of more questions than answers. Their strength gives us the conviction to effectively serve the increasing number of people who come to us for assistance. Their courage sets an example that we draw upon when our feelings of discouragement outweigh those of inspiration.

We also dedicate this guide to the People with AIDS who we have lost in the battle against this illness. Each has touched our lives in unique and special ways. Our enrichment is a timeless tribute to their memory.

Jennifer Lang  
Judy Spiegel  
Steve Strigle  
AIDS Project/Los Angeles

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Thank you all for contributing a valuable resource for people with AIDS, their loved ones, and care givers. We hope this guide can be as much help to yourselves and your organizations.

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# INTRODUCTION

The current epidemic of Acquired Immune Deficiency Syndrome (AIDS) with its associated opportunistic cancers and infections has affected thousands of individuals. Since the Centers for Disease Control (CDC) first reported the syndrome in June 1981, about 40% of the diagnosed cases have died. However, the statistics reflect only those cases that fit the stringent definition of the Center for Disease Control (CDC). Physicians caring for persons with AIDS note that there are three to five times as many individuals with the AIDS Related Complex (ARC, persons with AIDS-related illnesses who do not meet the CDC case definition) who have not been reported.

## Centers for Disease Control Surveillance Definition of Acquired Immunodeficiency Syndrome

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Presence of reliably diagnosed disease at least moderately indicative of underlying **cellular** immunodeficiency (Kaposi's sarcoma in a patient under 60 years of age, Pneumocystis carinii pneumonia or other opportunistic infections).

Absence of **known** causes of underlying immunodeficiency and of any other reduced resistance reported to be associated with the disease (immunosuppressive therapy lymphoreticular malignancy).

---

AIDS can be characterized as a chronic disease with progressively debilitating symptoms. The course of the disease varies among individuals and may run a relatively short, aggressive course or as long as a five year period. The epidemic is still too new to adequately predict the range or progress of disease in those affected. For the majority of their illness, persons with AIDS or ARC will be responsible for their own care. Although a substantial amount of educational material is directed at the risk reduction and recognition of signs and symptoms of AIDS, little information is available to assist those with AIDS in coping with and managing their illness, both physically and emotionally. The diagnosis of AIDS is accompanied by requirements for self-care activities that may not have been part of the pre-diagnosis self-care repertoire. The presence of fever, loss of appetite, weight loss, diarrhea, changes in metabolic patterns, and risk of opportunistic infections require specific self-care interventions in order to promote a sense of control, well-being, and to maintain life.

AIDS affects virtually every aspect of life. Personal relationships as well as professional goals may change. Financial resources may be limited due to lack of income, inadequate health insurance, and escalating medical costs. Legal assistance is often needed in responding to housing or job discrimination, drawing up wills, of assigning power of attorney. Perhaps more importantly is the task of coping with a potentially fatal illness — a job for which few people feel equipped.

The purpose of this manual is to provide information and resources for persons with AIDS, their families, significant others (friends, lovers), and caregivers, which will promote the ability to **LIVE** with AIDS. It is hoped that the information contained in this guide will promote a **sense of control** over situations where there **can be** some control, and assist in **cop**ing with situations in which there is little that can be done.



## GOALS

On the premise that self-care actions will improve coping and restore a sense of control, the goals of this manual are:

1. To provide comprehensive and readily accessible information about the history and physiological alterations associated with AIDS;
2. To provide the information needed to promote informed, competent participation and control in self-care activities which promote health and reduce risk;
3. To provide information needed to provide adequate and healthful home care for people with AIDS and AIDS-related illnesses;
4. To reduce anxiety by stating the expectations of health care providers, what expectations one should have of the health care system, and what the person with AIDS should expect of himself;
5. To improve coping skills through the provision of knowledge;
6. To provide information needed for appropriate utilization of community resources.

## RECOMMENDATIONS FOR USE

If you have just discovered that you have AIDS-related illness, you may be experiencing any number of different emotions. You may be wondering how you are going to cope. One of the best ways of coping with an illness is to learn all you can about it, and then participate actively in your own care. This approach has several advantages: it helps you to feel independent and in control (which can positively affect the course of your illness); it helps you to feel better about yourself; and it lets you help health care advisors give you the best care possible.

This manual is designed to provide you with the information you need to care for yourself and to participate actively in your own care. It can also assist all those concerned (friends, family, other caregivers) in defining their own role in your care and providing the tools to cope with the AIDS epidemic.

Self-care is based on the premise that for the majority of your illness you will be responsible for your own care — at home, not in a hospital setting. It does not mean that this is a substitute for professional medical care. Rather, it is a complement or supplement. The information herein is intended to help you enhance your life and health care.

This manual is laid out into two basic sections: (1) an explanation and history of AIDS and (2) practical self-care mechanisms. It will allow you to understand the underlying disease principles, identify early signs of infections thereby leading to earlier and more successful treatment, and finally, the means by which you can prevent unnecessary risks and protect yourself and those around you.

We recommend that you review the entire guide, but focus on particular sections as the need arises. We have tried to express concepts in laymen's terms so that it can be easily understood by all and with little energy; you are not expected to read the entire manual at once. Use it as a guide or reference, and consult with your physician or local AIDS organization when you have further questions. Remember: you are not alone. Others are here to help.



## **SECTION I**

### **AIDS – THE MEDICAL PICTURE**

- What Is Aids
- History of the Epidemic
- Epidemiology
- The Immune System

### **WHAT IS AIDS?**

Acquired Immune Deficiency Syndrome (AIDS) is the result of a defect in the immune system's ability to resist certain types of infections: those caused by viruses, fungi, parasites, and mycobacteria (tuberculosis-like organisms). In addition, resistance to certain types of cancer is also diminished.

Presently, little is known about how the immune system defect occurs or exactly what mechanisms are involved, so we are limited to describing AIDS as a collection of signs, symptoms, and laboratory findings which indicate the presence of the illness. The term "acquired" is used because people with AIDS are known to have normal immune system function prior to the onset of the syndrome. The organisms listed previously (viruses, fungi, parasites, and mycobacteria) which cause infections in persons with AIDS are commonly found in the everyday environment and do not affect individuals with normal immune system function. When they cause infections they are called "opportunistic". Opportunistic infections are also seen in others with suppressed immune system function such as patients with leukemia or in organ transplant recipients who have had their immune system function deliberately suppressed to prevent rejection of the transplant. The difference between AIDS and leukemia, or organ transplants is that the immune system suppression that occurs with AIDS is more severe and appears to be the result of an infectious agent (Most likely a recently identified virus).

AIDS has been termed an "epidemic" because the number of cases attributed to the syndrome has risen dramatically from none prior to 1979 to more than 4,000 at the present time. In fact, the number of cases reported to the Center for Disease Control has doubled approximately every six to eight months since June of 1981. It was projected that the escalating number of cases reported would level off in the beginning of 1984, but as of this writing, that has not occurred. The numbers continue to mount daily.

The AIDS epidemic involves at least three groups of individuals. The first two groups meet the Center for Disease Control (CDC) case definition of AIDS. Most seriously affected are those persons who have laboratory evidence of a severe immune system defect and who have had at least one potentially lethal opportunistic infection. The second group is comprised of persons under the age of 60 years who have Kaposi's Sarcoma. The third and largest group of affected individuals do not have as severe an immune system defect, have not had a life threatening opportunistic infection or Kaposi's Sarcoma, but do have other signs and symptoms associated with AIDS. Members of this group are said to have an AIDS Related Complex (ARC) and are not reported to the CDC as a case of AIDS. Statistics published by the CDC do not include individuals with symptoms of ARC, but several medical research centers are following this group.



**Centers for Disease Control  
Surveillance Definition of  
Acquired Immunodeficiency Syndrome**

---

Presence of reliably diagnosed disease at least moderately indicative of underlying **cellular** immunodeficiency (Kaposi's sarcoma in a patient under 60 years of age, *Pneumocystis carinii* pneumonia or other opportunistic infections).

Absence of **known** causes of underlying immunodeficiency and of any other reduced resistance reported to be associated with the disease (immunosuppressive therapy lymphoreticular malignancy).

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## **HISTORY OF THE EPIDEMIC**

**Stephen M. Strigle, B.S., CT (ASCP)**

In early summer 1981, five cases of *Pneumocystis carinii* pneumonia (PCP) were reported by the Centers for Disease Control (CDC) in Atlanta. All five cases were in previously healthy, sexually active, young homosexual men from Los Angeles, California. This reporting was quite unusual because PCP, a pneumonia caused by a parasitic organism, is seen almost exclusively in immune suppressed individuals. These men had no history of immune suppression, nor was there any reason to suspect that these five men would be immune suppressed. However, laboratory studies done on three of them revealed an abnormally decreased functioning of the immune system. (No immunologic studies were done on the other two cases.)

Around the same time, 26 cases of an unusual skin cancer, Kaposi's sarcoma, were reported to the CDC. Like the cases of pneumonia, the cancer was seen in homosexual men from Los Angeles as well as New York City. Until this point, Kaposi's sarcoma, a rare form of cancer, had been seen only in elderly men of Jewish or Mediterranean descent or in recipients of kidney transplants. The finding of this cancer in young homosexual men was extremely unusual.

With time, other types of unusual viral, fungal, and parasitic infections were being diagnosed in young homosexuals with similar immune defects. As the number of cases grew, it became apparent that these findings were not coincidental. Since it appeared that homosexual or bisexual men were almost exclusively affected, it was suspected that some aspect of the gay lifestyle was the probable cause of the immune deficiency, opportunistic infections, and cancer. Gay-related Immune Deficiency (GRID) became the name of this new and mysterious disease.

As physicians became more aware of GRID, more cases were reported. Doctors were prompted to investigate previously unexplainable cases that seemed to parallel the course of GRID. It soon became apparent that GRID was not limited to the homosexual/bisexual male population. These same conditions were diagnosed in another unique population of previously healthy individuals: heterosexual intravenous (IV) drug users. When tested, this group showed similar immune system defects. GRID was no longer an appropriate acronym and the name was changed to Acquired Immune Deficiency Syndrome (AIDS).

As cases of AIDS continued to be reported in these first two groups, a third high risk group was recognized. In New York and Miami, increasing numbers of Haitian immigrants presented with the same immune system abnormalities and opportunistic infections.



The seriousness of these reportings was not clearly understood until three heterosexual men with hemophilia A (non-drug users) developed AIDS and were reported to the CDC in July 1982. Hemophilia A is a blood clotting defect that requires the transfusion of blood clotting factors as part of therapy. Because these products came from pooled donated blood, it was suggested that AIDS had entered and was transmitted through the nation's blood supply. As new cases continued to be reported, four groups were labelled "high risk" categories: homosexual/bisexual men, IV drug users, Haitian immigrants and hemophiliacs.

The possibility of transmission of AIDS via blood was further substantiated when AIDS was diagnosed in adults and children who had received blood transfusions. When records were checked, it was found that some of the blood donors, although healthy at the time of donation, later developed AIDS.

Early attempts by researchers to isolate and identify a causative agent were unsuccessful, but the histories of those who had developed AIDS made it clear that there were two major factors involved in the transmission of AIDS: exposure to infected blood, or sexual contact with a person who either had or might have been carrying AIDS. The development of AIDS in IV drug users, in hemophiliacs who use Factor VIII (concentrated clotting factors derived from pooled blood), and in recipients of blood transfusions indicated that the "agent" could be transmitted through blood. The development of AIDS in homosexually active men, and in female sexual partners of men with AIDS indicated that AIDS was also sexually transmissible from men to men or women. In addition, it appeared that AIDS could be transmitted to the unborn children of women who either had AIDS themselves or who were sexual partners of men with AIDS. Since AIDS has been diagnosed in sexual partners and children (less than 2 years of age) of members of high risk groups not diagnosed with AIDS, it appears that a carrier state in which one can feel healthy but still transmit the causative agent may exist.

Nearly all cases of AIDS can be linked, in some way, to the four major risk groups — homosexual/bisexual men, IV drug users, hemophiliacs, and Haitian immigrants. There are, however, some isolated cases in which no link can be found; these cases account for less than 6% of all reported cases.

Though it has been diagnosed in only a few specified risk groups, AIDS remains a major health concern to us all. It is the health crisis of the 80's and one of the more puzzling epidemics in the history of medicine.

With the publication of the first report of AIDS in the **New England Journal of Medicine** in December 1981, there came a flurry of hypotheses about the possible causes of this new immune system defect in gay men. The frequency of sexually transmitted diseases; the use of amyl and butyl nitrate ("poppers"), steroid creams, lubricants and marijuana were all considered possible causes. However, the recognition of AIDS in persons who were not exposed to such agents soon discounted such theories.

Because it was recognized that the syndrome appeared to be transmitted in much the same way as Hepatitis B, a viral agent was considered the most likely candidate. The possibility was considered that it was a mutant strain of Cytomegalovirus or Epstein-Barr virus (both of which cause an infectious mononucleosis-like illness).

Not until early 1983 was there any indication that a virus first discovered in 1980, Human T-cell Leukemia/Lymphotropic virus (HTLV), might be the causative agent. In the May 1983 issue of **Science** researchers from the Institut Pasteur reported the finding of an antibody to HTLV in the blood of a patient with AIDS. In May 1984, both the National Institutes of Health and the Institut Pasteur reported the discovery of two new strains of viruses which researchers felt was responsible for AIDS. The NIH termed their virus discovery "Human T-lymphotropic virus" (HTLV-III), while the French termed their's "Lymphadenopathy Virus"



(LAV). Although it is possible that these two viruses are one and the same, this has not been confirmed as of this writing.

## EPIDEMIOLOGY

Since the first reports of AIDS, the populations at risk have remained the same with the exception of a gradually enlarging group of heterosexual men and women for whom no known risk exists. The incidence of blood transfusion-related AIDS remains relatively low with 46 possible transfusion-related cases known as of January 1984. There have been no reports to indicate that the syndrome has been transmitted from women to men.

The Centers for Disease Control monitors AIDS activity throughout the United States and publishes monthly statistics on newly reported cases. The following is an example of such information which can be obtained from your local Health Department. (See Table) While the numbers are increasing, the percentage breakdowns remain fairly constant. About 6% of all AIDS cases belong to an "unknown" risk category. Included in this group are blood transfusion recipients, women who are sexual partners of men in high risk groups, and individuals who have died prior to giving a detailed personal history.

**TABLE 1**

### ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) WEEKLY SURVEILLANCE REPORT — UNITED STATES

AIDS ACTIVITY  
CENTER FOR INFECTIOUS DISEASES  
CENTERS FOR DISEASE CONTROL  
May 28, 1984

#### UNITED STATES CASES REPORTED TO CDC

| 1. PRIMARY DISEASE*  | CASES | PERCENT OF TOTAL |
|----------------------|-------|------------------|
| KS without PCP       | 1153  | 25.0             |
| PCP without KS       | 2403  | 52.1             |
| Both KS and PCP      | 299   | 6.5              |
| OI without KS or PCP | 760   | 16.5             |
| Total                | 4615  | 100.0            |

\*KS = Kaposi's sarcoma

PCP = Pneumocystis carinii pneumonia

OI = other opportunistic infections

| 2. AGE   | CASES | PERCENT OF TOTAL | 3. RACE/ETHNICITY   | CASES | PERCENT OF TOTAL |
|----------|-------|------------------|---------------------|-------|------------------|
| Under 20 | 26    | 0.6              | White, not Hispanic | 2690  | 58.3             |
| 20 - 29  | 1008  | 21.8             | Black, not Hispanic | 1162  | 25.2             |
| 30 - 39  | 2156  | 46.7             | Hispanic            | 661   | 14.3             |
| 40 - 49  | 989   | 21.4             | Other               | 14    | 0.3              |
| Over 49  | 405   | 8.8              | Unknown             | 88    | 1.9              |
| Unknown  | 31    | 0.7              | Total               | 4615  | 100.0            |
| Total    | 4615  | 100.0            |                     |       |                  |

| 4. Patient Characteristics** | MALES |                  | FEMALES |                    | TOTAL |                  |
|------------------------------|-------|------------------|---------|--------------------|-------|------------------|
|                              | CASES | PERCENT OF MALES | CASES   | PERCENT OF FEMALES | CASES | PERCENT OF TOTAL |
| Homosexual or Bisexual       | 3328  | 77.3             | 0       | 0.0                | 3328  | 72.1             |
| Intravenous (IV) Drug User   | 621   | 14.4             | 172     | 55.3               | 793   | 17.2             |
| Haitian                      | 154   | 3.6              | 27      | 8.7                | 181   | 3.9              |
| Hemophilic                   | 33    | 0.8              | 0       | 0.0                | 33    | 0.7              |
| None/Apparent/Unknown        | 168   | 3.9              | 112     | 36.0               | 280   | 6.1              |
| Total                        | 4304  | 100.0            | 311     | 100.0              | 4615  | 100.0            |

\*\*Patient characteristics listed are ordered hierarchically; cases with multiple characteristics are tabulated only in the group listed first.



## THE IMMUNE SYSTEM

The immune system defends the body against infections and some cancers. It is composed of white blood cells, lymph nodes, and lymphatic ducts. There are five main types of white blood cells, and all are involved in either fighting infections or destroying foreign invaders.

Among the various types of white blood cells are lymphocytes, a primary component of the immune system. Lymphocytes are the cells most affected by AIDS. Their function is to identify foreign invaders (antigens) as being “not self”, or not part of the body’s normal make-up, and then provoke immune responses which result in the antigen’s destruction and elimination.

Just as there are several types of white blood cells, there are different kinds of lymphocytes. The two major classifications are T-lymphocytes and B-lymphocytes, so named because of their origins (the thymus and bone marrow, respectively). T-lymphocytes are involved in controlling immune responses and, to a degree, B-lymphocytes. B-lymphocytes are involved primarily in antibody production (immunoglobulins).

### Lymph Nodes

Lymph nodes serve as centers for lymphocyte production and the removal of foreign debris which accumulates when lymphocytes are fighting an infection. In the absence of infection, lymph nodes cannot be felt. However, when infection or reaction to infection is present, the lymph nodes located near the infection site enlarge and become obvious to the touch. The presence of enlarged lymph nodes is called lymphadenopathy. Lymph nodes are located above the collar bones and in the neck, armpits, and groin.

### Humoral Immunity

Humoral immunity is a function of B-lymphocytes and is associated with the production of immunoglobulins or antibodies. Antibodies are essentially chains of protein which circulate through the blood stream. They are generally produced in response to an infection or vaccination (deliberate exposure to an altered infectious agent to promote immunity), and the protein chains provide long lasting protection from recurrence or re-exposure to infectious agents. For example, when a child is exposed to Rubella (German measles), he/she experiences a brief illness and develops antibodies to the Rubella virus. Those antibodies will continue to circulate through the body indefinitely, to protect against future infections from Rubella. Then in adulthood if the antibody levels are measured (as in the Rubella titer required for women in premarital blood tests), one should still see evidence of antibodies to Rubella.

Humoral immunity for infections experienced prior to the development of AIDS is not adversely affected despite the association between T- and B-lymphocytes. The ability to fight most bacterial infections (for example a strep throat) remains normal. In fact, for reasons not yet identified, persons with AIDS often have high levels of certain types of immunoglobulins (IgG and IgA). However, persons with AIDS do not seem to be able to develop antibodies to infections acquired after the development of the syndrome — Hepatitis B, for example.

### Cell-Mediated Immunity

Cell-mediated (cellbound) immunity is controlled by lymphocytes and provides resistance against viruses, fungi, protozoa, and mycobacteria (tuberculosis-like organisms). AIDS specifically damages this part of the immune system by altering the characteristics, numbers, and functions of the lymphocytes. T-lymphocytes are the central actors in this system and are the most seriously affected by AIDS.

There are three types of T-lymphocytes: (1) T-helpers (Th) which stimulate an immune response; (2) T-suppressors (Ts) which limit or inhibit immune response, and (3) T-killers (Tk) which directly destroy foreign invaders or antigens. T-killers are especially important in



the destruction of fungi, protozoa, viruses, and certain cancers. T-lymphocytes communicate through the release of chemicals known as lymphokines such as interferon. Lymphokines can also amplify an immune response.

T-lymphocytes become sensitized or stimulated after initial exposure to a foreign invader or antigen. When subsequently exposed to the same antigen, they cause the production of substances such as interferon which strengthen this immune response. When the response is no longer needed, T-suppressor cells control or suppress the immune activity.

In order to understand fully the affect of AIDS on the immune system and the mechanisms of treatment, a short discussion of the antigen-recognition process should be helpful: All body cells and infectious agents are coated by proteins. The structure and arrangements of these proteins is so consistent for each type of cell or infectious agent that they can be easily distinguished from each other on the basis of their protein surface coatings. When matching potential organ transplant donors and recipients, the tissue typing that takes place is aimed at getting the closest possible match between the protein organization (tissue type) of donor and recipient. In human cells, the protein arrangement is genetically coded and every individual has his/her own genetic makeup (with the exception of identical twins).

Foreign proteins are referred to as **antigens**. Under normal circumstances the presence of antigens provokes an immune response. In AIDS, however, the total numbers of lymphocytes is depleted; but more specifically, there is a dominant number of T-suppressors due to a reduction of the T-helpers. Because T-suppressors dominate or prevent immune responses to fungi, protozoa, and viruses, opportunistic infections occur. Such infections are also seen in patients whose immune system is deliberately suppressed to prevent rejection of a graft or organ transplant.

## **Human T-Cell Leukemia/Lymphotropic Virus**

Human T-Cell Leukemia/Lymphotropic viruses (HTLV), a type of retrovirus (referring to the way in which the virus is genetically coded), have been recognized for only a few years. They have a specific attraction to T-helper lymphocytes. Similarly, AIDS affects T-helper lymphocytes by actually reducing the numbers present in circulation and by affecting the cell surface proteins of the lymphocytes. Consequently, the small number of T-helper lymphocytes are unable to recognize or react to the presence of viruses, fungi, protozoa, mycobacteria, or cancer cells. HTLV-III (a third variety of HTLV) has been implicated as the cause of AIDS. The link between the newly discovered strain of HTLV (termed Lymphadenopathy Virus by the Pasteur Institute in France) and AIDS is not conclusively established at this time, but the effects on T-helper lymphocytes caused by the virus and the alterations seen in AIDS appear to be the same.



## SECTION II

### AIDS RELATED ILLNESS AND INFECTIONS

- AIDS Related Complex & Lymphadenopathy
- Opportunistic Infections
- Kaposi's Sarcoma

#### AIDS RELATED COMPLEX AND LYMPHADENOPATHY

Jennifer Lang, M.N., R.N.

Persistent Generalized Lymphadenopathy Syndrome (PGL) is currently defined by the Centers for Disease Control as:

- (1) lymphadenopathy (lymph node swelling) of at least 3 months duration, involving at least 2 sites other than the groin, without evidence of an illness or drug use known to cause lymphadenopathy; and
- (2) the presence of increased lymph node activity (reactive hyperplasia) as diagnosed by a lymph node biopsy.

The relationship of persistent generalized lymphadenopathy to AIDS is not clear at this time. Many gay men have been known to have had PGL for many years without developing AIDS.

Symptoms such as fever, drenching night sweats, weight loss, fatigue and lymphadenopathy in the **absence** of an opportunistic infection or Kaposi's Sarcoma have come to be known as AIDS Related Complex (ARC). Symptoms of ARC have been known to exist for several months prior to the development of AIDS or Kaposi's Sarcoma. However, only a small percentage of people with these symptoms have actually developed opportunistic infections or Kaposi's Sarcoma. Still others have developed AIDS without any preceding symptoms.

Whether PGL or ARC are actually prodromes (precursors to the disease) or a milder form of AIDS remains the subject of debate. Researchers across the country are currently following patients with these symptoms to determine how many actually develop CDC defined AIDS.

#### OPPORTUNISTIC INFECTIONS

Jennifer Lang, M.N., R.N.

Opportunistic infections are caused by organisms which commonly occur in the environment and to which persons with a normally functioning cell mediated immune system have a natural resistance. Only when there is immune suppression can these viruses, fungi, protozoa, and mycobacteria seize the "opportunity" to cause infection. Both persons with AIDS and others who have had cell mediated immune system function deliberately suppressed (to prevent rejection of organ transplants) are at risk of developing opportunistic infections. In AIDS the frequency and seriousness of the opportunistic infections is greater. The organisms causing opportunistic infections are listed here and those that are most problematic for people with AIDS are discussed in greater depth in the self-care section.



**Viruses** — The viral infections most commonly seen in persons with AIDS are caused by members of the herpes virus family. Cytomegalovirus (CMV), Epstein-Barr Virus (EBV), Herpes Simplex I (cold sores), Herpes Simplex II (genital herpes) and Herpes Zoster (shingles) are all frequently seen.

Both CMV and EBV cause infectious mononucleosis-like illnesses with fevers, sweats, loss of appetite, sore throat, lymphadenopathy and severe fatigue of several weeks duration. Occasionally an infection can occur without any symptoms. Both CMV and EBV can be transmitted in urine, saliva, sputum and semen. Commonly called "the kissing disease," these infections are very common in all segments of the population, but even more so among gay men. Both CMV and EBV are known as chronic viruses which remain dormant in the body after an initial infection and then are capable of reactivating during periods of immunosuppression. Most, if not all persons with AIDS, demonstrate active CMV and/or EBV infections during the course of AIDS. In the immunosuppressed person with AIDS, CMV may be the cause of pneumonia, gastrointestinal symptoms (vomiting and diarrhea), hepatitis or impaired vision.

Herpes Simplex I and II (cold sores and genital herpes, respectively) with AIDS differ from that found in normal immune system function in that the sores may last longer, be more difficult to heal, and be more likely to spread to other locations.

Herpes Zoster (shingles) occurs as a result of reactivation of an old chickenpox virus which has lain dormant since childhood along the lining of a nerve. Although frequently seen in older people who do not have AIDS, the shingles seen with AIDS takes longer to heal, is more likely to spread, and may require hospital treatment with an antiviral drug.

**Fungi** — *Candida* and *Cryptococcus* are two fungi frequently seen in persons with AIDS. *Candida* is very commonly found on the mucus membranes of the mouth and vagina. In AIDS, *Candida* overgrows on the mucus membranes of the mouth, gastrointestinal tract, and sometimes in internal organs. When infecting the mouth, it is known as thrush and is associated with visible creamy white patches, reddened mucus membranes and some discomfort in chewing and swallowing.

*Cryptococcus neoformans* is a fungus which is inhaled into the lungs, but most commonly it infects the lining of the brain causing headaches, blurred vision, confusion, depression, uncontrolled excitement and inappropriate speech.

**Protozoa** — The protozoans *Pneumocystis carinii*, *Cryptosporidia*, and *Toxoplasma gondii* are responsible for three major opportunistic infections. *Pneumocystis carinii* causes a pneumonia which develops slowly and is not easily recognized in its early stages. *Pneumocystis carinii* pneumonia (PCP) is the most common of all the opportunistic infections. *Cryptosporidiosis* is the name given to a diarrheal infection caused by the protozoan *cryptosporidia*. This organism attaches itself to the lining of the small and large intestines and prevents absorption of nutrients. The diarrhea is severe, with frequent watery stools and abdominal cramping. *Toxoplasmosis*, transmitted hand to mouth primarily from cat feces, is a common infection with very few symptoms in most segments of the population. In AIDS, *toxoplasmosis* tends to be more severe, causing an inflammation of the brain with fevers, changes in ability to move, and personality or behavior changes.

**Mycobacteria** — The most commonly known member of this family, *M. tuberculosis*, which causes lung tuberculosis is only rarely seen in persons with AIDS. More frequently *Mycobacterium avium-intracellulare* (*M. avium*) infects the blood stream, internal organs, bone marrow, and lymph nodes, but rarely the lungs. The most common symptom is fever. Persons with normal immune system function are not at risk of developing *M. avium*.



# **KAPOSI'S SARCOMA**

**Ronald Mitsuyasu, M.D.**

## **EPIDEMIC VS. CLASSICAL**

Kaposi's Sarcoma, one of the opportunistic conditions seen in AIDS, is not a new cancer. On the contrary, it has been known to exist in a classic, non-fatal form for over a century and is found in another form in parts of Africa. This section will discuss Kaposi's Sarcoma as it appears in its classic European origin, endemic African framework, and most recently AIDS related epidemic form.

**Classical:** Kaposi's Sarcoma was first described over a century ago by the Hungarian dermatologist, Moricz Kaposi, as a slow-growing tumor affecting primarily elderly men of Ashkenazi Jewish or Mediterranean origin. Although the term sarcoma (which means soft tissue tumor) is used, this is probably a misnomer as the tumor arises primarily from the inner wall of blood vessels. In the classic or traditional form of this disease, the tumor arises primarily on the lower legs of elderly males and follows a relatively limited and painless course. Tumors are treated easily with local radiation to the involved areas, or if more extensive, by chemotherapy with drugs such as vinblastine (Velban). The tumor is easily controlled, with most individuals dying of diseases other than Kaposi's Sarcoma.

**Endemic African:** A second form of Kaposi's Sarcoma occurs commonly in equatorial Africa and comprises up to 10% of all cancers among the Bantu tribes of Zaire and Uganda. The disease occurs in younger individuals and generally follows a more rapidly growing course in African patients. The geographic distribution of cases in Africa parallels the so called "lymphoma belt" of Burkitt's lymphoma, a tumor which is closely associated with Epstein-Barr virus. It has therefore been postulated that Kaposi's Sarcoma may also be associated with a virus.

**Epidemic:** Recently a similarly aggressive form of Kaposi's Sarcoma has been seen among homosexually active males in association with the Acquired Immunodeficiency Syndrome. The tumor ordinarily does not occur in this age range (under the age of 60) in any substantial number and can, therefore, be called a true epidemic. In AIDS the tumor, which looks very similar to the classic form of Kaposi's Sarcoma, may occur anywhere on the body and frequently involves internal organs at a fairly early stage in its development. Microscopically, the tumor appears identical to that seen among older Jewish men or African patients. However, the characteristics of the tumor are such that many experts feel that it may, in fact, be different.

## **DESCRIPTION**

The appearance and progression of Kaposi's Sarcoma are largely determined by the situation in which the tumor arises. In the classical form occurring in elderly Caucasian males, the tumor grows slowly and is generally restricted to the lower legs. The endemic African form of Kaposi's Sarcoma has more widespread skin involvement and may start with lymph node swelling.

The epidemic form of Kaposi's Sarcoma associated with AIDS usually appears as painless purple to brownish, slightly raised spots on the skin or mucous membranes of the mouth. The skin lesions may appear anywhere on the body including the skin of the feet, legs or arms, face, neck, chest or back. Lymph nodes and internal organs can also be involved. In most cases these do not cause the patient any discomfort. The gastrointestinal tract is the most common site of internal involvement with Kaposi's Sarcoma, and often times it can be detected only through direct examination with a specialized instrument called an endoscope. On rare occasions the lungs and other organs are involved, but usually this does not occur until the disease has spread in its final stages. Individuals who develop new or unusual appearing discolorations of bumps on their skin (and belong to



any one of the high risk groups for AIDS) should consult their physician or dermatologist for a skin biopsy to rule out the possibility of Kaposi's Sarcoma. This is particularly important as these lesions generally do not cause any symptoms.

The course of the tumor varies from individual to individual. However, among homosexual men Kaposi's Sarcoma tends to spread more rapidly than among the elderly Jewish population. Because of this, it is recommended that patients with the diagnosis of Kaposi's Sarcoma be evaluated for underlying immune abnormalities associated with AIDS, and if detected, should be referred to a practicing oncologist (cancer specialist) or university teaching center for appropriate treatment.

### **WHY DOES IT OCCUR?**

The cause of Kaposi's Sarcoma is, as yet, not clearly defined. There is mounting evidence that underlying immunodeficiency may allow the development of Kaposi's Sarcoma as well as other cancers. Cases of Kaposi's Sarcoma have occurred in people receiving immunosuppressive drugs to prevent rejection of a transplanted kidney and among those receiving cancer chemotherapy, which also suppresses the immune system. The geographic distribution of Kaposi's Sarcoma may be related to viral infections. There is some evidence that cytomegalovirus, a common virus which ordinarily does not cause a problem in the healthy host, may cause cells to become malignant (cancerous), as in Kaposi's Sarcoma when immunodeficiency is present. It is believed that repeated exposure to this virus or other similar viruses (such as through the secretions of homosexual men) may contribute to the immunodeficiency and possibly the malignancies associated with AIDS. In addition, there may be a certain genetic predisposition to develop Kaposi's Sarcoma in individuals with AIDS. A disproportionate prevalence of one tissue typing antigen, HLA-DR5, has been reported among patients with AIDS who develop Kaposi's Sarcoma. Further investigations in the epidemiology, virology, and immunology of patients with AIDS and Kaposi's Sarcoma may ultimately yield answers as to why this unusual tumor occurs in the setting of AIDS.



## SECTION III

- Diagnosis of AIDS
- Medical Treatment of AIDS
- Medical Treatment of Kaposi's Sarcoma

### DIAGNOSIS OF AIDS

Jennifer Lang, M.N., R.N.

At the time of this writing there is no single test which will determine the presence of AIDS. With the recent recognition of HTLV as a possible causative agent, there is promise that a blood test will soon be developed. However, the accuracy and reliability of such a blood test will take several years of experience.

Presently, the diagnostic tests performed depend largely on the patient's history and the physician's concerns. A greater than 3 month history of fevers, night sweats, weight loss, and lymphadenopathy in a sexual partner or member of a high risk group would certainly raise suspicion of AIDS. The presence of an opportunistic infection or skin lesions resembling Kaposi's Sarcoma would raise suspicions even higher.

Depending on the physician's concerns, the diagnostic process may include:

1. Complete physical examination.
2. Routine blood tests:
  - a) Chemistry panel — to check general function including that of liver and kidneys
  - b) VDRL — a routine test for syphilis
  - c) Complete blood count — to check for anemia, and white blood cell counts.
3. Radiologic studies (x-rays)
  - a) Chest x-ray — to look for lung infection
  - b) Abdominal CAT Scan — to evaluate for the presence of lymphadenopathy in the abdomen if other enlarged lymph nodes are present.
4. Upper gastrointestinal endoscopy and flexible sigmoidoscopy to look for gastrointestinal KS, candidiasis, CMV or cryptosporidiosis (endoscopy is the insertion of a small flexible tube to closely examine specific organs)
5. Biopsy of skin lesions suspicious for KS or lymph nodes if exclusively large.
6. Blood tests for the presence of antibodies to CMV or EBV (CMV or EBV titers).
7. Viral cultures of blood, semen, or urine for CMV.
8. Stool culture and examination for the presence of parasites or their eggs (giardia, amoeba, etc.) if indicated by the presence of diarrhea or other abdominal symptoms.
9. Tests for immune system function.

### How Is Immune System Function Measured?

No single test measures immune function. In fact, there are more tests than can be listed here. When reviewed with the patient's history, the results of several tests provide an overall picture of immune system function. The following tests have been useful in



diagnosing AIDS: White blood cell count (WBC), total lymphocyte count, T-cell subsets, quantitative immunoglobulins, and delayed hypersensitivity skin tests. All are blood tests, except the delayed hypersensitivity skin tests.

**White Blood Cell Count:** Experience has shown that patients who develop opportunistic infections usually have white blood cell (WBC) counts of less than 3,500. WBC's are usually normal (3,500 – 10,000) in patients with persistent lymphadenopathy or Kaposi's Sarcoma only. The risk of opportunistic infection is higher in patients with WBC's less than 3,500.

**Total Lymphocyte Count:** A normal lymphocyte count is greater than 1,500; when less than 1,000 it is called absolute lymphopenia. Lymphopenia is seen in persons with opportunistic infections, in one half of persons with Kaposi's Sarcoma, but not in persons with persistent generalized lymphadenopathy. The risk of developing an opportunistic infection is substantially higher in patients with absolute lymphopenia.

**T-cell subsets:** Although it is not 100% reliable, this analysis of blood T-cell subpopulations is the single most sensitive test for AIDS-related illness. T-lymphocytes are separated into T-helper and T-suppressor populations. The relationship of T-helper to T-suppressor cells is usually expressed as a ratio and is normally greater than 1.0 (with the percentage of helper cells equal to or greater than suppressor cells). Low ratios do not always indicate AIDS since low helper-to-suppressor ratios can also be seen in patients with viral infections such as uncomplicated cytomegalovirus, hepatitis B, and in infectious mononucleosis caused by Epstein-Barr virus. The T-helper to T-suppressor ratio is significantly decreased in AIDS with opportunistic infection and in persistent lymphadenopathy, but not as significantly in Kaposi's Sarcoma. In individual patient situations the best indicators of immune system function are the absolute lymphocyte count and the percentage of T-helper cells.

**Quantitative Immunoglobulins:** Circulating immunoglobulins (antibodies) in the blood can be measured. There are five classes of immunoglobulins: IgG, IgA, IgM, IgD, and IgE. In AIDS the levels of IgA and IgG are frequently elevated.

**Delayed Hypersensitivity Skin Tests:** By injecting a small amount of liquid antigen, such as the protein from mumps, into the skin on the forearm, it is possible to determine the ability of the immune system to recognize or remember foreign substances. In a normal response, redness and swelling occur when antigens are introduced to which the body has been previously exposed. Antigens commonly used are purified solutions of candida (a fungus), mumps (a virus), tetanus (a bacteria), tuberculosis (a mycobacterium). All of these antigens are purified and will not cause infections themselves.

If a reaction occurs, it becomes apparent about 24 hours following injection; maximal response usually occurs at 48-72 hours. A positive reaction is one in which the diameter of swelling exceeds 5-10 millimeters (about ¼ inch) in at least one of the antigen injection sites. In the past, you may have been given a tuberculosis skin test and been reassured when no reaction developed. This means you had not previously been exposed to the TB antigen, and therefore no recognition or immune response occurred.

When AIDS is suspected, a **positive** reaction to at least one of the antigens is more reassuring. Most people have been exposed to tetanus, mumps or candida, and a positive reaction shows that the immune system recognizes the antigen from past exposure. Lack of any response to any antigen is termed **anergy** and is frequently seen in individuals with opportunistic infections, Kaposi's Sarcoma and about one-half of those affected with persistent lymphadenopathy.

**Other Immune Function Tests:** Two other tests are frequently done to evaluate immune function: lymphocyte transformation studies and natural killer cell activity levels. Transformation studies in AIDS patients have shown markedly decreased ability to transform lymphocytes when exposed to certain chemical agents. Natural killer cell activity is likewise



markedly decreased.

The above tests measure only immune function and cannot detect or diagnose the opportunistic infections and cancers of the syndrome. They do show, however, a “pattern” that is seen in most AIDS patients. This pattern—decreased WBC, lymphocyte count, H/S ratio, natural killer cell activity, transformation ability, anergy, and increased IgA,G levels — when present, may be a sign of AIDS and even though the patient may present no symptoms at that time, he/she should be closely monitored.

## **I HAVE NO SYMPTOMS BUT WANT TO CHECK MY IMMUNE SYSTEM FUNCTION. WHAT SHOULD I DO?**

As previously mentioned, if you are asymptomatic (without symptoms) you may never know your immune system is deficient. With the current concern over getting AIDS, many people want to check their immune system. **Before** you go running to your doctor asking for all the tests, consider the following points:

1. Do you consider yourself at risk? Just because you are gay or from Haiti, does not mean you are destined to get AIDS.
2. These tests are expensive. Can you afford them?
3. Should you have all the tests, one, or two of them?
4. If the results come back within normal limits the first time, that does not mean your immune system will be normal forever. How often should you have these tests?

As a whole, most doctors do NOT recommend this entire series of tests for the individual that is just “curious” — primarily because they are too expensive. Discuss your concerns with your doctor. What he/she will probably recommend is a CBC (complete blood count) and from that procedure will be able to check your white blood count and lymphocyte count. Since these are low in most AIDS patients, that may give a fairly good indication of your immune system status.

## **I HAVE THE SYMPTOMS OF THE “PRODROME”: FEVER/NIGHT SWEATS, WEIGHT LOSS AND LYMPHADENOPATHY.**

Fever is one of the body’s natural responses to inflammation/infection. Along with night sweats, these are nonspecific symptoms seen in a multitude of conditions with no single test pinpointing their etiology (cause). Likewise, weight loss is too non-specific to have a diagnostic test suggesting what causes it.

On the other hand, the cause(s) of lymphadenopathy can sometimes be determined. Lymphadenopathy can be caused by many bacterial, fungal, protozoan, or viral conditions whether or not one has AIDS. It can also be seen in cancer and metabolic disorders. When infection is present, the nodes located near the site of the infection enlarge and can be felt. Many times simple blood tests can determine the cause of the lymphadenopathy if it has an infectious origin. If blood tests are unable to detect a cause, it may be necessary to perform either a lymph node biopsy or aspiration biopsy/cytology on the enlarged node. In some cases of Kaposi’s Sarcoma, the tumor has been confined to the nodes and wasn’t seen on the skin. Other tumors, especially lymphomas, can be diagnosed on node biopsies.

In AIDS patients or generalized lymphadenopathy, the biopsy usually reveals a non-specific pattern known as reactive hyperplasia.



## **I HAVE SOME OF THE SYMPTOMS SEEN IN AIDS.**

Many times patients do not consult a doctor until specific symptoms are seen. These symptoms, mentioned earlier in the text, require further tests to determine their origin. These tests that may be required to explain some of the symptoms of AIDS follows:

**Persistent, unexplained diarrhea or blood stools:** Diarrhea can occur for any number of reasons: infection, diet, malabsorption, and psychological reasons, to name a few. Persistent diarrhea **must** be investigated. A stool specimen should be collected to determine the presence of a bacteria or parasite. If the bacterial culture and microscopic exam for ova (eggs) and parasites (like amoeba) are negative, an infectious process cannot necessarily be ruled out.

Cryptosporidium, one of the opportunistic infections of AIDS causes persistent diarrhea, but it cannot be grown by routine bacterial culture and is very difficult, if not impossible, to find on routine exam for stool parasites. What is necessary to diagnose the Cryptosporidium is a tissue biopsy of the intestinal lining. This is accomplished by visualizing the intestines using a sigmoidoscope, locating a suspicious area, and taking the biopsy. The tissue is then processed and examined microscopically, to determine the presence of the small parasite sitting on the cells lining the intestinal tract. Positive cultures or tests should be followed by antibiotics to kill the diarrhea-causing agent. If after treatment, the diarrhea subsides, then it was apparently due to some bacteria or parasite other than Cryptosporidium.

Bloody stools can be due to a number of things like ulcerative colitis, infectious organisms, or a tumor. To determine the presence of blood in the stool, the doctor should do a Guaiac test, a simple office procedure, on a sample of your stool. If it is positive for blood, further studies are needed to determine the cause. Any blood in the stool, outside small amounts due to straining, is abnormal and should be investigated.

**Persistent white coat (or spotting) on tongue:** This usually indicates candidiasis (also known as thrush moniliasis). Most of the time, it can be visibly recognized. The suspected area can be scraped and then stained, microscopically showing budding yeast cells, compatible with candida.

**Persistent shortness of breath accompanied by persistent dry cough:** Pulmonary (lung) problems are commonly seen in AIDS. Infections due to Pneumocystis carinii, cytomegalovirus, candida, herpes, and toxoplasma can occur. Essential to the diagnosis of any pulmonary pathology (disease process) is a chest x-ray. The x-ray usually shows a pulmonary infiltrate (a haziness or cloudiness to the film due to fluid build-up in the lung tissue). Any number of things can cause these infiltrates; the presence/absence of an infectious agent must be determined.

Many different types of specimens may be taken to identify an infectious agent, some more complicated to obtain than others. Sputum is easily obtained, but may not accurately indicate what is happening **deep** inside the lung. What the patient may think is sputum, may in reality be mostly saliva and does not adequately give the doctor a "picture" of what is occurring deep inside the lung. The following are choice specimens for the identification of pulmonary infections: tracheal (windpipe) aspiration, bronchial washing/brushing/biopsy, lung aspiration/biopsy. Once the specimen is collected, the diagnosis can be made by special staining procedures, as in Pneumocystis carinii infection, or by culture, as in bacterial, viral, and fungal infections (cryptococcus, herpes, candida). Besides being cultured, viral or fungal infections can also be determined microscopically by identifying the organism structures on slides.

To determine if the infectious agent affects the amount of oxygen in the blood, blood



from an **artery** is taken (rather than a vein). Arterial blood gases can then be determined; they quantify gas or oxygen exchange in the blood.

*Pneumocystis carinii*, the most common and serious of the opportunistic lung infections associated with AIDS, usually shows a severe decrease of oxygen in the blood.

**Easy bruising/unexplained bleeding:** This symptom has been seen in some sexually active homosexual males without the presence of any opportunistic infections. Unusual in healthy individuals, its presence in AIDS is unclear and should not be ignored.

The easy bruising and prolonged bleeding is caused by a decrease in the number of platelets (cells essential to blood clotting) in the blood. This condition is known as autoimmune thrombocytopenic purpura, ATP). To determine the number of platelets in the blood, blood from a vein must be taken and a platelet count done. Normally, platelets live for 7-10 days, but in ATP they last only 1-3 days. Other clotting studies that can be done are bleeding times, clot retraction, and bone marrow aspirations.

**Blurred vision and/or headaches (and other neurological problems):** Eye problems can result from the opportunistic AIDS infections. Cotton wool spots on the retina can develop, blurring the vision and making sight itself painful. Sometimes organisms like cytomegalovirus can be cultured from the eye. A thorough eye exam will reveal the presence of cotton wool spots or any infectious agent.

Central nervous system involvement with AIDS results from infections due to organisms like *Cryptococcus* and *Toxoplasma gondii*. Usually the first prominent sign of cryptococcal involvement is an increasingly painful headache. Dizziness, vision disorders and mental deterioration can develop.

The diagnosis of *Cryptococcus* can be done one of two ways:

- 1) blood tests for the presence of cryptococcal antigen.

- 2) microscopic exam of cerebrospinal fluid for the budding yeast cells seen in *Cryptococcus neoformans*. *Cryptococcus* in spinal fluid provides a poor prognosis.

Encephalitis is a common manifestation of *Toxoplasma* infection, but *Toxoplasma* can also occur without any symptoms. If it progresses unnoticed, seizures and cerebral hardening can develop. Identification of *Toxoplasma gondii* can be done, one of two ways:

- 1) a blood test for the presence of antibodies to *Toxoplasma*

- 2) identification of the organism in cerebrospinal fluid, sputum, blood, or other body fluids.

Any visual impairments require a thorough eye exam.

**Enlarging, discolored nodules, plaques on the skin:** Kaposi's sarcoma can be seen on the skin, in internal organs or both. Diagnosis of suspected skin lesions is done by a biopsy, direct examination of a removed portion of the suspicious lesion. If lymphadenopathy occurs with the skin lesions, the enlargement may be just reactive hyperplasia (as mentioned earlier). On occasion, however, Kaposi's occurs in the lymph nodes, so the enlarged node should be biopsied. Kaposi's can also occur internally and without symptoms. If skin lesions are diagnosed as Kaposi's Sarcoma, it is a good idea to do further studies and see if any internal Kaposi's lesions exist. The tests are upper and lower endoscopy and sigmoidoscopy to look for gastrointestinal lesions, and bronchoscopy to look for pulmonary lesions. Kaposi's can also occur in the mouth. A thorough oral exam by an oral pathologist or dentist should be done, with a biopsy performed of any suspected lesion.

Other tests that might be done are: viral titers and cultures for cytomegalovirus and Epstein-Barr viral antibodies or organisms.

In summary it is important to re-emphasize that the presence of one or a few of these symptoms is NOT an automatic diagnosis of AIDS. Tests may show you are immune defi-



cient, and if you consider yourself to be a high risk individual, you should be followed closely by a physician. Lastly, if you have symptoms, but no evidence of the opportunistic infections of AIDS, remember that something is causing these symptoms. Check them out!

## **MEDICAL TREATMENT OF AIDS**

**Jennifer Lang, R.N., M.N.**

In the short period of time since the first reports of AIDS in 1981, major scientific breakthroughs have been accomplished. A developing understanding regarding the epidemiology of AIDS, immune system function, identification of viruses, and treatment of opportunistic infections create a foundation of knowledge upon which an effective treatment for AIDS can be built. Researchers in many centers around the world are working to find the answers needed to combat AIDS on several levels. The development of a screening test is progressing to identify carriers and persons infected with AIDS who have not yet developed symptoms. Although this may become available in research centers in the near future, it will be several years before the accuracy and reliability of such a test can be determined and made available to the general public.

The development of a vaccine to prevent AIDS may also become available on an experimental basis in the near future. Since vaccines for the HTLV type of virus may be difficult to develop, it may still take some years of trial and error before an ideal vaccine is commercially available. The development of a drug which acts directly against the AIDS virus is also a possibility, but none has been identified to date. Drugs which modify or promote immune system function (in this case, T-helper lymphocyte function) such as interferon, interleukin-2, and thymic hormones show promise and are currently being tested.

For those who currently have AIDS, the primary approach is exploration — drugs which modify immune system function, and early observation and aggressive management of opportunistic infections.

## **MEDICAL TREATMENT OF KAPOSI'S SARCOMA**

**Ronald Mitsuyasu, M.D.**

Since our experience with the epidemic form of Kaposi's Sarcoma and AIDS is brief, the development of an effective treatment for KS has been hindered. We lack a clear understanding of the cause of the tumor and the mechanisms affecting the underlying immune deficiency. For the majority of patients, the opportunistic infections which occur as a result of AIDS are more problematic than Kaposi's Sarcoma tumors. However, as immune system function becomes worse, the growth of the tumor does seem to accelerate.

In the classic form of Kaposi's Sarcoma occurring in elderly Jewish males with relatively normal immune system function (immune system function normally deteriorates with age) the tumor is easily controlled with local radiation therapy or chemotherapy. When Kaposi's Sarcoma has developed as a result of deliberate suppression of immune system function (to prevent the rejection of a kidney transplant), stopping the immunosuppressive medications has resulted in disappearance of the tumors.

The epidemic form of Kaposi's Sarcoma which is seen with AIDS tends to grow more rapidly and has not responded as well to the conventional treatments for this tumor. This has stimulated the development of new treatment approaches with experimental agents such as interferon. These are aimed at stimulating immune system function. An understanding of the currently available approaches should assist the person with AIDS in deciding what type of treatment to pursue.



## Radiotherapy

Skin lesions appear to be highly sensitive to radiotherapy (x-ray treatment). Radiation treatment with either Cobalt or electron beams directed at the site of the skin lesions is the treatment of choice for alleviating such tumors. Radiation is generally successful in causing shrinkage or disappearance of tumors in the specific treated area, but it does not cure the disease or affect tumors outside of the site of radiation.

In the setting of AIDS when the tumor grows more rapidly, radiation has been reserved primarily for the treatment of painful lesions or tumors interfering with the function of vital organs. When lesions cause swelling of the skin or have an obviously unsightly cosmetic effect, radiation may also be considered.

A new experimental approach called "hemi-body irradiation" uses high doses of irradiation delivered to one half of the body at a time. This treatment has been used with patients who have widespread Kaposi's Sarcoma. Its side effects include local skin irritation from the radiation beam, some nausea, occasional mouth sores, diarrhea, and lowered blood counts in some individuals. Hemi-body irradiation has brought about shrinkage and sometimes disappearance of Kaposi's Sarcoma lesions, but the aggravation of underlying opportunistic infections has been a complication of this approach. Since hemi-body irradiation does not deal with the tumor on a total body basis, KS tumors may recur.

## Chemotherapy

Chemotherapeutic agents are medications administered **into the blood stream** which act to prevent the multiplication of rapidly growing cells. Cancer cells are the desired target of chemotherapy, but other rapidly growing cells are also affected such as those that produce hair, the mucus membrane linings of the mouth and gastrointestinal tract, and blood cells (white blood cells, platelets and red blood cells).

Several chemotherapy drugs have been used in the treatment of Kaposi's Sarcoma. The classic form of KS has been very sensitive and responsive to conventional treatments with drugs such as vinblastine (Velban), and actinomycin-D. In contrast, the epidemic AIDS form of Kaposi's grows more rapidly and does not respond as readily to these treatments. Furthermore, patients are more likely to develop opportunistic infections. Most AIDS patients start chemotherapy with lower than normal blood counts, and chemotherapy further affects the bone marrow's ability to produce new blood cells. Consequently, safe types and doses of chemotherapy drugs may be severely limited.

For those who are able to receive chemotherapy, several drugs have been found to be helpful. Conventional drugs such as vinblastine (Velban), and vincristine (Oncovin) have helped some patients. Newer, experimental agents such as VP-16 or razazone (ICRF) have also provided responses.

Giving more than one chemotherapy agent at the same time (combination chemotherapy) has both benefits and disadvantages. By using drugs in combination which interfere differently with tumor cell growth or which act at different stages of cell reproduction, there is a higher likelihood that more tumor cells will be destroyed with one chemotherapy treatment. The disadvantage is that there are generally more side effects when combining several chemotherapy drugs. An effective combination chemotherapy regimen presently in use includes three drugs: adriamycin, vinblastine, and bleomycin (known as ABV). Each of these drugs alone has an effect on the treatment of KS but all have side effects which include temporary lowering of blood counts, temporary hair loss, nausea, diarrhea, occasional fatigue, and fever. Many of these side effects limit the drug dose that can be safely administered.

Frequent blood tests are necessary to monitor for the effects of chemotherapy on blood counts, liver and kidney function. Lowering of white blood cell counts below a certain



level may allow the development of infections which are a problem in view of the underlying immunodeficiency of AIDS. A lowered platelet count may increase the possibility of bleeding. Careful observation of these problems by both the patient and his physician may decrease the possibility of their occurrence.

As yet, there is no "best treatment" for Kaposi's Sarcoma with AIDS. Each approach has both advantages and disadvantages. It is possible that our present inability to restore normal immune system function will limit the effectiveness of chemotherapy in the setting of AIDS.

## **Biologic Modifiers**

While the goal of radiation and chemotherapy is the destruction of cancerous cells, biologic modifiers act to assist, boost or amplify the natural body mechanisms in controlling and eliminating deviant cells. Immunotherapy is a form of biologic modification in that the desired result is strengthening natural immune system responses. Presumably, since the epidemic form of Kaposi's Sarcoma develops in association with immune deficiency (AIDS), it may be particularly responsive to immunotherapy.

Agents such as interferon, which are capable of regulating some immune system responses as well as acting directly against viruses and tumor cells, have particular appeal as a method of treating AIDS associated Kaposi's Sarcoma. Several research projects have already demonstrated the activity of interferon in shrinking and sometimes eliminating KS lesions in persons with AIDS. One form of interferon, known as Alpha Interferon, was found to cause as much as an overall 40% tumor shrinkage rate in studies conducted at the University of California, Los Angeles, San Francisco General Hospital, and Memorial Sloan-Kettering Hospital in New York.

Side effects of interferon include fatigue and weakness, fevers, muscle aches, occasional diarrhea and some hair loss with long term use. Occasional recurrence of tumors has occurred despite the overall high response rate. Reduced blood counts and liver function tests may occur and can affect the amount of interferon that may be safely administered. These results, while encouraging are still preliminary and further study of this agent both alone and in combination with chemotherapeutic agents will be necessary to establish its overall role in the treatment of Kaposi's Sarcoma.

Other biologic modifiers which may have a direct influence on the immune system include agents such as gamma and beta interferon, interleukin 2, and various thymic hormone preparations. These agents are currently being tested in limited fashion at selected medical research centers around the country. Their ultimate role in the treatment of Kaposi's Sarcoma or in improving the immune system has yet to be established. Caution should be advised in deciding on experimental treatment approaches. Patients should seek out reputable medical oncologists (cancer specialists) preferably at university teaching hospitals where careful monitoring for side effects and thorough evaluation of the effectiveness of these agents can be established.



## **SECTION IV**

### **SELF CARE TECHNIQUES**

- Nutrition and Exercise
- Dental Care
- General Hygiene and Risk Reduction
- Home Care
- Symptom Management
- Managing the Side Effects of Kaposi's Sarcoma
- Managing the Side Effects of Treatment Kaposi's Sarcoma

### **NUTRITION AND EXERCISE**

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Nutritional consideration in the self care of persons with AIDS cannot be overemphasized. While fevers and infections create an increased metabolic rate and increased need for protein and calorie intake, limiting factors such as diarrhea and loss of appetite make it difficult to meet such needs. Poor nutrition may also contribute further to suppression of cell-mediated immunity; many scientific studies have shown that protein-calorie malnutrition reduces the numbers and effectiveness of circulating lymphocytes. While maintaining an optimal nutritional state will not cure AIDS, it could positively influence the numbers and function of lymphocytes, and resistance to opportunistic infections.

Protein is essential to produce new cells and repair damaged tissues whenever the body is stressed, as it is when fighting infections. When this need for protein cannot be met through dietary intake, the body breaks down muscle tissue and recycles these muscle proteins (the "building blocks of life") into new production and tissue formation.

The body is more likely to steal proteins from muscles which are not being used. Therefore, inactivity as well as poor protein-calorie intake, and infection, all contribute to the "wasting" syndrome that is so commonly seen in AIDS. In order to prevent muscle deterioration, it is important that both nutrition and exercise receive equal attention.

#### **HOW DO I MEET MY NUTRITIONAL NEEDS?**

Healthy people who are not stressed by infection or increased activity normally need about 2700 calories and 56 grams of protein for men and 2000 calories and 45 grams of protein for women just to maintain their weight. During an illness such as AIDS, the requirement goes up to as much as 5000 calories per day. A good rule of thumb is to try for 50 calories per kilogram (2.2 pounds) of ideal body weight with 1.5 grams of protein per Kg. For a 155 pound (70 Kg) man this would be 3500 calories per day with 105 grams of protein. In addition to protein and calories, it is important to maintain a well balanced diet which will supply minerals, vitamins and other elements. This can be accomplished by choosing foods from each of the basic four food groups. Multivitamin supplementation is recommended in moderation, but only with consultation with a physician.

#### **WHAT ARE THE BASIC FOUR FOOD GROUPS?**

**Fruit and Vegetable Group:** Four servings a day of salads, cooked vegetables, raw or cooked fruits or juices supply needed vitamins and minerals. A serving can consist of



one-half cup of cooked vegetables, fruit or juice or one cup or one piece of raw fruit or vegetables.

**Meat Group:** Three servings per day of fish, poultry, eggs or cheese provide protein as well as many vitamins and minerals. A serving is two ounces of meat, fish or poultry or two eggs or two ounces of cheese or one cup of dried beans, peas or nuts, or four tablespoons of peanut butter.

**Grain Group:** Four servings a day of grains and cereals supply a variety of vitamins, minerals and some protein. A serving is one slice of bread or one cup of cereal or one-half cup of pasta, rice or grits.

**Milk Group:** Two servings a day of each of milk or other dairy products provide protein, various vitamins and calcium. One serving is one cup of yogurt or milk, one and one-half ounces of cheese, one cup pudding, one and three-quarters cup of ice cream or two cups of cottage cheese.

## **PROBLEMS WITH EATING**

**No Appetite:** Lack of appetite (anorexia) is common among people with AIDS for many reasons including depression, fatigue, nausea and infection. Some approaches to dealing with lack of appetite include the following:

**a) Altered Sense of Taste:** Protein foods are a problem. Red meat in particular has been reported to be either tasteless or metallic, like mush or sawdust. Play with seasonings, or try using pickles or lemon juice on your meat. Switch to poultry or fish. Since appetite is usually better in the morning, try to get at least one-third of the days calorie and protein requirements into the breakfast meal. Eating the dinner meal at breakfast-time is worth considering. Use custards, eggnogs or commercial liquid supplements between meals. Experiment with food temperatures. Room temperature or cold foods that are high in protein (ice cream, gelatin salads with cottage cheese and fruit stuffed with nut butters) may have a more acceptable taste.

**Depression:** For most, eating is a social event, and thus atmosphere definitely makes a difference in appetite. Share meal times with others when possible (make them promise not to nag you first). An attractive table setting, flowers, a glass of wine and music will go a long way towards making eating more enjoyable.

**Fatigue:** Too tired to cook or go out for food? Invest in a microwave oven and get friends to help stock your freezer with appetizing high protein main courses. Cook favorite dishes when your energy level is up and freeze them for the "blah" times.

**Getting Full Too Fast:** This is a common problem which can be partially resolved by eating small servings more frequently, chewing foods slowly and thoroughly, and reducing fluid intake with meals. Make part of the liquid you drink with your meals as nourishing as the meal itself by using nutritional supplements (Sustacal, Ensure, etc.) "on the rocks". The secret to meeting nutritional needs, in this case, is to get as many calories into as small a package as possible. Sauces, gravies, and nutritional supplements make this task much easier.

**Nausea:** The smell of cooking food may contribute to your desire to eat. Have someone else cook, or try fresh fruits and uncooked foods such as cottage cheese or cold soups. Greasy or fried foods may be a problem; avoid them. If nausea is a big problem, discuss it with your doctor. He may be able to prescribe an anti-nausea medication which can be taken about 30 minutes before meals.

**Diarrhea:** May be exacerbated by food intake, especially when caused by lactose intolerance, high fiber or high fat diets.

**Lactose Intolerance:** Lactose is a milk sugar found primarily in milk and dairy products and added to many other foods. It requires an intestinal enzyme (lactase) to promote its



digestion and absorption. When lactase is lacking, diarrhea, gas, or cramping may occur. Many adults lack this enzyme. Lactose production may be inhibited by intestinal infection, antibiotics or other treatments. Persons with AIDS can determine whether lactose intolerance is contributing to diarrhea by observing the effects of eliminating dairy products and high lactose foods from their diet. High lactose foods include milk, ice cream, cheese (except natural cheese aged 90 days or more), instant coffee, cocoa, chocolate and most chocolate beverages, cream and desserts with custard or cream filling. Soy bean formulas, such as those sold as infant formulas, can be used to substitute for dairy products in many cases.

**High Fiber diets:** increase bulk and stimulate intestinal movement. Reducing intake of whole grains in bread or cereals, fresh fruits and vegetables will reduce fiber content.

**High Fat diets:** Fried or greasy foods and meats with high fat contents may exacerbate diarrhea.

The booklet **Eating Hints** published by the U.S. Department of Health and Human Services provides many low lactose, low fat, high calorie, high protein recipes.

## **WHAT NUTRITIONAL SUPPLEMENTS CAN I USE TO INCREASE MY CALORIE INTAKE?**

There are many commercially prepared supplements available, all of which have their own special merits. Reading labels is particularly important when trying to decide which products best meet your unique needs. Some of the characteristics you need to consider include the following:

**Flavor:** various flavors available from vanilla to black walnut. Unflavored types can be flavored with your own extracts i.e. mint, rum, etc.

**Milk or Soy based** — if problems with lactose intolerance, choose soy based formulas.

**Calories** — the calorie concentration varies from brand to brand. Isocal HCN and Magnacal have the highest number of calories per serving while Isomil has the lowest.

**Taste** — Some products taste better “on the rocks” while others are better at room temperature. Taste varies from person to person, so it's better to try them yourself rather than relying on the reports of others.

Powders are worth evaluating in terms of how they can be added to other foods to fortify protein and calorie content. One powder is worthy of note — **Polycose** is a glucose polymer which is not very sweet, so it can be added to or sprinkled on just about anything (including lettuce) to increase calorie content. Polycose does not have any other nutritional value, but for adding calories it's worth using.

## **HOW ELSE CAN I ADD CALORIES AND PROTEIN TO MY DIET?**

Fortify milk by adding one cup nonfat dry milk to one quart homogenized or low-fat milk.

Add butter or margarine (45 cal/tsp.) to everything imaginable.

Use mayonnaise (100 cal/tbsp.) as a salad dressing.

Spread peanut butter (90 cal/tbsp.) on fruit or bread.

Use sour cream (70 cal/tbsp.) or yogurt as a vegetable dip, sauce and in gravies.

Put whipped cream (60 cal/tbsp.) on desserts and jello salads.

## **EXERCISE**

Exercise is important for maintaining circulation, muscle mass and improving your sense of well-being. If you are able to get out, a walking regimen is good. Lifting weights is useful for everyone including those who spend a great deal of time in bed. It is important to remember that exercising just until the point of fatigue is good, but pushing yourself much beyond may be detrimental. You may wish to consult your physician or a physical therapist to determine how to exercise with the safest benefits.



# NUTRITIVE VALUE OF COMMON FOODS<sup>†</sup>

|                                              | Amt  | Calo-<br>ries | Pro-<br>tein<br>(g) | Fat<br>(g) | Carbo-<br>hydrate<br>(g) | Cal-<br>cium<br>(mg) | Phos-<br>phorus<br>(mg) | Iron<br>(mg) | Sodium<br>(mg) | Potas-<br>sium<br>(mg) | Vit. A<br>(I.U.) | Thiamine<br>(mg) | Ribo-<br>flavin<br>(mg) | Niacin<br>(mg) | Ascorbic<br>Acid<br>(mg) | USDA<br>Handbook<br>No. 456<br>Ref. No. |
|----------------------------------------------|------|---------------|---------------------|------------|--------------------------|----------------------|-------------------------|--------------|----------------|------------------------|------------------|------------------|-------------------------|----------------|--------------------------|-----------------------------------------|
| <b>Milk</b>                                  |      |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| Buttermilk                                   | 1 C  | 88            | 8.8                 | 0.2        | 12.5                     | 296                  | 233                     | 0.1          | 319            | 343                    | 10               | 0.10             | 0.44                    | 0.2            | 2                        | 509b                                    |
| Milk, skim                                   | 1 C  | 88            | 8.8                 | 0.2        | 12.5                     | 296                  | 233                     | 0.1          | 127            | 355                    | 10               | 0.09             | 0.44                    | 0.2            | 2                        | 1322b                                   |
| Milk, whole                                  | 1 C  | 159           | 8.5                 | 8.5        | 12.0                     | 288                  | 227                     | 0.1          | 122            | 351                    | 350              | 0.07             | 0.41                    | 0.2            | 2                        | 1320b                                   |
| <b>Vegetables</b>                            |      |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| *Asparagus                                   | 4    |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 47b                                     |
| Green beans, frozen,<br>french style         | ½ C  | 14            | 1.2                 | 0.1        | 3.1                      | 19                   | 25                      | 0.5          | 1              | 99                     | 443              | 0.07             | 0.08                    | 0.5            | 10                       | 194c                                    |
| Beans, lima (frozen)                         | ½ C  | 84            | 5.1                 | 0.1        | 16.2                     | 17                   | 77                      | 1.5          | 86             | 362                    | 195              | 0.06             | 0.03                    | 0.9            | 15                       | 173c                                    |
| Beets                                        | ½ C  | 27            | 1.0                 | 0.1        | 6.1                      | 12                   | 20                      | 0.5          | 37             | 177                    | 15               | 0.03             | 0.04                    | 0.3            | 5                        | 385b                                    |
| *Beet greens, spinach,<br>collards (cooked)  | ½ C  | 22            | 2.5                 | 0.4        | 3.5                      | 111                  | 34                      | 1.4          | 33             | 260                    | 6133             | 0.07             | 0.14                    | 0.6            | 36                       | 393a, 2170a,<br>807a                    |
| *Brussel sprouts, frozen                     | ½ C  |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 492c                                    |
| Cabbage, raw                                 | 1 C  | 21            | 1.7                 | 0.2        | 4.2                      | 25                   | 34                      | 0.5          | 12             | 189                    | 200              | 0.06             | 0.06                    | 0.4            | 47                       | 512c                                    |
| Cauliflower                                  | ½ C  |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 631a                                    |
| Corn on cob, 5" (boiled)                     | 1    | 70            | 2.5                 | 0.8        | 16.2                     | 2                    | 69                      | 0.5          | —              | 151                    | 310              | 0.09             | 0.08                    | 1.1            | 7                        | 846a                                    |
| Peas, green, frozen                          | ½ C  | 55            | 4.1                 | 0.3        | 9.5                      | 15                   | 69                      | 1.5          | 92             | 108                    | 480              | 0.22             | 0.07                    | 1.4            | 11                       | 1530c                                   |
| Potato, french fried<br>(2" to 3½" diameter) | 10   | 137           | 2.2                 | 6.6        | 18.0                     | 8                    | 56                      | 0.7          | 3              | 427                    | —                | 0.07             | 0.04                    | 1.6            | 11                       | 1789b                                   |
| Potato, sweet, mashed                        | ¼ C  | 73            | 1.1                 | 0.3        | 16.8                     | 21                   | 30                      | 0.5          | 7              | 155                    | 5038             | 0.06             | 0.04                    | 0.4            | 11                       | 2250c                                   |
| Potato, white, baked<br>(2" diameter)        | ½ C  | 59            | 1.7                 | 0.1        | 13.3                     | 6                    | 41                      | 0.5          | 3              | 316                    | —                | 0.07             | 0.03                    | 1.2            | 13                       | 1787d                                   |
| *Pumpkin, carrots, winter<br>squash          | ½ C  | 37            | 1.1                 | 0.3        | 8.9                      | 27                   | 32                      | 0.5          | 10             | 261                    | 6757             | 0.04             | 0.08                    | 0.6            | 7                        | 1832d, 620a,<br>2201a                   |
| Rutabagas, mashed                            | ½ C  | 42            | 1.1                 | 0.1        | 9.9                      | 71                   | 37                      | 0.4          | 5              | 201                    | 660              | 0.07             | 0.07                    | 1.0            | 31                       | 1920b                                   |
| *Summer squash                               | ½ C  |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 2192a                                   |
| Celery, stalks                               | 3    |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 637c                                    |
| Cucumbers, slices                            | 16   | 9             | 0.7                 | 0.1        | 2.1                      | 19                   | 17                      | 0.6          | 18             | 133                    | 290              | 0.03             | 0.04                    | 0.3            | 6                        | 942d                                    |
| Lettuce, shredded                            | 1 C  |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 1256c                                   |
| *Tomatoes, canned & juice                    | ½ C  | 24            | 1.2                 | 0.2        | 5.2                      | 8                    | 23                      | 0.9          | 200            | 269                    | 1028             | 0.06             | 0.04                    | 0.9            | 20                       | 2284d, 2288d                            |
| Tomatoes, fresh<br>(2½" diameter)            | 1    | 20            | 1.0                 | 0.2        | 4.3                      | 12                   | 25                      | 0.5          | 3              | 222                    | 820              | 0.05             | 0.04                    | 0.6            | 21                       | 2282c                                   |
| Turnips, mashed                              | ½ C  | 26            | 0.9                 | 0.3        | 5.7                      | 41                   | 28                      | 0.5          | 39             | 216                    | —                | 0.05             | 0.06                    | 0.4            | 26                       | 2353b                                   |
| <b>Fruits</b>                                |      |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| Apple (2½" diameter)                         | 1    | 61            | 0.2                 | 0.6        | 15.3                     | 7                    | 11                      | 0.3          | 1              | 116                    | 100              | 0.03             | 0.02                    | 0.1            | 4                        | 13d                                     |
| Applesauce, unsweetened                      | ½ C  | 50            | 0.3                 | 0.3        | 13.2                     | 5                    | 6                       | 0.6          | 3              | 95                     | 50               | 0.03             | 0.01                    | 0.1            | 1                        | 28e                                     |
| Banana, medium                               | ½    | 51            | 0.7                 | 0.1        | 13.2                     | 5                    | 16                      | 0.4          | 1              | 220                    | 115              | 0.03             | 0.04                    | 0.4            | 6                        | 141b                                    |
| *Berries (blue, black,<br>raspberries)       | ½ C  | 46            | 0.8                 | 0.4        | 10.9                     | 19                   | 15                      | 0.8          | 1              | 113                    | 118              | 0.02             | 0.04                    | 0.4            | 10                       | 424b, 418a,<br>1851a                    |
| Cantaloupe (¼ of 6"<br>diameter)             | 1 C  | 48            | 1.1                 | 0.2        | 12.0                     | 22                   | 26                      | 0.6          | 19             | 402                    | 5440             | 0.06             | 0.05                    | 1.0            | 53                       | 1358c                                   |
| Citrus Fruit:                                |      |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| *Orange/grapefruit juice                     | ½ C  |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          | 1421c, 1053b,<br>1437b, 1061a           |
| Orange, small                                | 1    | 49            | 0.8                 | 0.1        | 11.8                     | 19                   | 19                      | 0.3          | 1              | 189                    | 158              | 0.08             | 0.3                     | 0.3            | 49                       |                                         |
| Grapefruit                                   | ½    |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| Cherries, large                              | 10   | 47            | 0.9                 | 0.2        | 11.7                     | 15                   | 13                      | 0.3          | 1              | 129                    | 70               | 0.03             | 0.04                    | 0.3            | 7                        | 663b                                    |
| Grapes                                       | 12   | 41            | 0.4                 | 0.2        | 10.4                     | 7                    | 12                      | 0.2          | 2              | 104                    | 60               | 0.04             | 0.02                    | 0.2            | 2                        | 1085a                                   |
| Pears, water pack                            | 1    | 50            | 0.4                 | 0.4        | 12.8                     | 8                    | 10                      | 0.4          | 2              | 136                    | —                | 0.02             | 0.04                    | 0.2            | 2                        | 1504e                                   |
| Raisins (½ T)                                | ½ oz | 40            | 0.4                 | —          | 10.8                     | 9                    | 14                      | 0.5          | 4              | 107                    | —                | 0.02             | 0.01                    | 0.1            | —                        | 1846c                                   |
| Strawberries                                 | 1 C  | 55            | 1.0                 | 0.7        | 12.5                     | 31                   | 31                      | 1.5          | 1              | 244                    | 90               | 0.04             | 0.10                    | 0.9            | 88                       | 2217e                                   |
| Watermelon, diced                            | 1 C  | 42            | 0.8                 | 0.3        | 10.2                     | 11                   | 16                      | 0.8          | 2              | 160                    | 940              | 0.05             | 0.05                    | 0.3            | 11                       | 2424c                                   |
| <b>Bread &amp; Crackers, Enriched</b>        |      |               |                     |            |                          |                      |                         |              |                |                        |                  |                  |                         |                |                          |                                         |
| Biscuit (2" diameter,<br>1¼" high)           | 1    | 103           | 2.1                 | 4.8        | 12.8                     | 34                   | 49                      | 0.4          | 175            | 33                     | —                | 0.06             | 0.06                    | 0.5            | —                        | 410a                                    |
| Cornbread, piece<br>(2½"x2½"x1½")            | 1    | 178           | 3.8                 | 5.8        | 27.5                     | 133                  | 209                     | 0.8          | 263            | 61                     | 130              | 0.10             | 0.10                    | 0.8            | —                        | 1350d                                   |
| Frankfurter roll (6")                        | 1    | 119           | 3.3                 | 2.2        | 21.2                     | 30                   | 34                      | 0.8          | 202            | 38                     | —                | 0.11             | 0.07                    | 0.9            | —                        | 1902c                                   |
| Graham crackers                              | 2    | 55            | 1.1                 | 1.3        | 10.4                     | 6                    | 21                      | 0.2          | 95             | 55                     | —                | 0.01             | 0.03                    | 0.2            | —                        | 914b                                    |
| Hamburger bun (3½")                          | 1    | 119           | 3.3                 | 2.2        | 21.2                     | 30                   | 34                      | 0.8          | 202            | 38                     | —                | 0.11             | 0.07                    | 0.9            | —                        | 1902c                                   |
| Muffin, plain (2"x1½")                       | 1    | 118           | 3.1                 | 4.0        | 16.9                     | 42                   | 60                      | 0.6          | 176            | 50                     | 40               | 0.07             | 0.09                    | 0.6            | —                        | 1343b                                   |
| Saltines (2½" square)                        | 4    | 48            | 1.0                 | 1.3        | 8.0                      | 2                    | 10                      | 0.1          | 123            | 13                     | —                | —                | —                       | 0.1            | —                        | 916d                                    |
| Soda crackers<br>(2½" square)                | 5    | 65            | 1.3                 | 1.8        | 10.0                     | 3                    | 13                      | 0.2          | 156            | 16                     | —                | —                | —                       | 0.1            | —                        | 918d                                    |
| White or whole wheat bread,<br>slice         | 1    | 76            | 2.4                 | 0.9        | 14.1                     | 24                   | 27                      | 0.7          | 142            | 29                     | —                | 0.07             | 0.06                    | 0.7            | —                        | 461b                                    |



|                                             |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
|---------------------------------------------|---------|-----|------|------|------|-----|-----|-----|-----|-----|-------|------|------|-----|-----|----------------------------|
| <b>Cereals, Enriched</b>                    |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| Bran flakes, 40%                            | ½ C     | 53  | 1.8  | 0.3  | 14.1 | 10  | 63  | 6.2 | 104 | 68  | 825   | 0.20 | 0.25 | 2.1 | 6   | 441                        |
| Corn flakes                                 | ¾ C     | 73  | 1.5  | 0.1  | 15.9 | —   | 7   | 0.4 | 188 | 22  | 885   | 0.22 | 0.26 | 2.2 | 7   | 866a                       |
| Farina, cooked                              | ½ C     | 51  | 1.6  | 0.1  | 10.6 | 5   | 15  | —   | 176 | 11  | —     | 0.05 | 0.03 | 0.5 | —   | 992                        |
| Grits, corn                                 | ½ C     | 62  | 1.4  | 0.1  | 13.5 | 1   | 13  | 0.4 | 251 | 14  | 75    | 0.05 | 0.04 | 0.5 | —   | 863a                       |
| Oatmeal, cooked                             | ½ C     | 66  | 2.4  | 1.2  | 11.6 | 11  | 68  | 0.7 | 262 | 73  | —     | 0.09 | 0.02 | 0.1 | —   | 1391                       |
| Rice, cooked                                | ⅓ C     | 74  | 1.4  | 0.1  | 16.4 | 7   | 19  | 0.6 | 256 | 19  | —     | 0.08 | 0.01 | 0.7 | —   | 1872a                      |
| Wheat, puffed                               | 1 C     | 54  | 2.3  | 0.2  | 11.8 | 4   | 48  | 0.6 | 1   | 51  | —     | 0.08 | 0.03 | 1.2 | —   | 2458                       |
| <b>Pasta, Enriched</b>                      |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| *Noodles, macaroni, spaghetti               | ½ C     | 91  | 3.0  | 0.6  | 18.3 | 7   | 41  | 0.7 | 1   | 43  | —     | 0.11 | 0.07 | 1.2 | —   | 1378c, 1299c, 2159c        |
| <b>Meat, Poultry, Fish</b>                  |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| *Beef, lamb, veal                           | 1 oz    | 79  | 7.4  | 5.2  | —    | 3   | 32  | 0.8 | 16  | 74  | 2     | 0.03 | 0.07 | 1.6 | —   | 353d, 1185e, 2370e         |
| Beef liver                                  | 1 oz    | 65  | 7.5  | 3.0  | 1.5  | 3   | 135 | 2.5 | 52  | 108 | 15130 | 0.07 | 1.19 | 4.7 | 7.7 | 1267a                      |
| Bologna (1 slice, 4½" diameter)             | 1 oz    | 86  | 3.4  | 7.8  | 0.3  | 2   | 36  | 0.5 | 369 | 65  | —     | 0.05 | 0.06 | 0.7 | —   | 1982g                      |
| Chicken, light meat                         | 1 oz    | 50  | 9.4  | 1.0  | —    | 3   | 80  | 0.4 | 19  | 123 | 17    | 0.01 | 0.02 | 3.5 | —   | 682d                       |
| *Cod, haddock, halibut (broiled)            | 1 oz    | 48  | 6.9  | 1.8  | 0.5  | 8   | 73  | 0.3 | 40  | 121 | 80    | 0.01 | 0.02 | 1.4 | —   | 795d, 1110d, 1104d         |
| Ham, cured                                  | 1 oz    | 92  | 6.3  | 7.1  | —    | 3   | 52  | 0.8 | 227 | 71  | —     | 0.15 | 0.06 | 1.1 | —   | 1779f                      |
| Hot dog                                     | 1       | 139 | 5.6  | 12.4 | 0.8  | 3   | 60  | 0.9 | 495 | 99  | —     | 0.07 | 0.09 | 1.2 | —   | 1994c                      |
| Pork, fresh                                 | 1 oz    | 103 | 6.8  | 8.1  | —    | 3   | 73  | 0.9 | 17  | 78  | —     | 0.26 | 0.07 | 1.6 | —   | 1716e                      |
| Shrimp                                      | 1 oz    | 37  | 7.7  | 0.4  | 0.2  | 37  | 84  | 1.0 | —   | 39  | 20    | —    | 0.01 | 0.6 | —   | 2045c                      |
| Tuna, canned in oil                         | 1 oz    | 82  | 6.9  | 5.8  | —    | 2   | 83  | 0.3 | 227 | 85  | 26    | 0.01 | 0.02 | 2.9 | —   | 2323h                      |
| Egg, large                                  | 1       | 82  | 6.5  | 5.8  | 0.5  | 27  | 103 | 1.2 | 61  | 65  | 590   | 0.05 | 0.15 | —   | —   | 968b                       |
| <b>Cheese</b>                               |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| Cheddar, domestic                           | 1 oz    | 113 | 7.1  | 9.1  | 0.6  | 213 | 136 | 0.3 | 198 | 23  | 370   | 0.01 | 0.13 | —   | —   | 646p                       |
| Cottage cheese, small curd, creamed         | ½ C     | 112 | 14.3 | 4.4  | 3.1  | 98  | 160 | 0.3 | 241 | 90  | 180   | 0.03 | 0.26 | 0.1 | —   | 647d                       |
| Peanut Butter                               | 2 T     | 188 | 8.0  | 16.2 | 6.0  | 18  | 122 | 0.6 | 194 | 200 | —     | 0.04 | 0.04 | 4.8 | —   | 1499f                      |
| <b>Dried Beans &amp; Peas</b>               |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| *Navy beans, kidney beans, split peas       | ½ C     | 114 | 7.5  | 0.4  | 20.6 | 32  | 123 | 2.2 | 8   | 342 | 15    | 0.12 | 0.07 | 0.8 | —   | 115b, 161d, 1533a          |
| <b>Fats</b>                                 |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| Bacon, crisp, slices                        | 2       | 86  | 3.8  | 7.8  | 0.5  | 2   | 34  | 0.5 | 153 | 35  | —     | 0.08 | 0.05 | 0.8 | —   | 126d                       |
| *Cream, light, 20% or Half & Half           | 1 T     | 26  | 0.5  | 2.5  | 0.7  | 16  | 13  | —   | 7   | 19  | 100   | —    | 0.02 | —   | —   | 929b, 928b                 |
| *French or Italian dressing                 | 1 T     | 75  | 0.1  | 7.6  | 1.9  | 2   | 2   | 0.1 | 267 | 8   | —     | —    | —    | —   | —   | 1932b, 1936b               |
| *Margarine/butter                           | 1 t     | 34  | —    | 3.8  | —    | 1   | 1   | —   | 46  | 1   | 160   | —    | —    | —   | —   | 1317d, 505d                |
| *Mayonnaise, salad dressing                 | 1 T     | 83  | 0.2  | 8.8  | 1.3  | 3   | 4   | 0.1 | 86  | 3   | 35    | —    | —    | —   | —   | 1938b, 1940b               |
| Oils                                        | 1 T     | 120 | —    | 13.6 | —    | —   | —   | —   | —   | —   | —     | —    | —    | —   | —   | 1401j                      |
| <b>Nuts</b>                                 |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| *Unsalted peanuts, pecans, walnuts, almonds | 2 T     | 103 | 2.9  | 9.6  | 2.9  | 20  | 64  | 0.5 | 19  | 102 | 5     | 0.07 | 0.05 | 1.0 | —   | 1496b, 1536j, 2421e, 8f    |
| <b>Desserts</b>                             |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| Brownies, with nuts (1¼"x1¾"x7/8")          | 1       | 97  | 1.3  | 6.3  | 10.2 | 8   | 30  | 0.4 | 50  | 38  | 40    | 0.04 | 0.02 | 0.1 | —   | 813                        |
| Cake, chocolate (3"x3"x2")                  | 1 piece | 322 | 4.2  | 15.1 | 45.8 | 65  | 121 | 0.8 | 259 | 123 | 130   | 0.02 | 0.09 | 0.2 | —   | 525c                       |
| Cake, plain (3"x3"x2")                      | 1 piece | 313 | 3.9  | 12.0 | 48.1 | 55  | 88  | 0.3 | 258 | 68  | 150   | 0.02 | 0.08 | 0.2 | —   | 534b                       |
| Chocolate pudding                           | ½ C     | 193 | 4.1  | 6.1  | 33.4 | 125 | 128 | 0.7 | 73  | 223 | 195   | 0.03 | 0.18 | 0.2 | —   | 1823                       |
| Cookies, chocolate chip                     | 2       | 99  | 1.1  | 4.4  | 14.6 | 8   | 24  | 0.4 | 84  | 28  | 26    | 0.01 | 0.01 | 0.1 | —   | 818b                       |
| Custard, baked                              | ½ C     | 153 | 7.2  | 7.3  | 14.7 | 149 | 155 | 0.6 | 105 | 194 | 465   | 0.06 | 0.25 | 0.2 | —   | 948                        |
| Gelatin dessert                             | ½ C     | 71  | 1.8  | —    | 16.9 | —   | —   | —   | 61  | —   | —     | —    | —    | —   | —   | 1032b                      |
| Ice cream, vanilla                          | 4 fl oz | 129 | 3.0  | 7.0  | 13.9 | 97  | 77  | 0.1 | 42  | 121 | 295   | 0.03 | 0.14 | 0.1 | —   | 1139d                      |
| Pie, apple (9" diameter)                    | ⅓ pie   | 302 | 2.6  | 13.1 | 45.0 | 9   | 26  | 0.4 | 355 | 94  | 40    | 0.02 | 0.02 | 0.5 | 1   | 1566c                      |
| Sherbert, orange                            | 4 fl oz | 130 | 0.9  | 1.2  | 29.7 | 16  | 13  | —   | 10  | 21  | 60    | 0.01 | 0.03 | —   | 2   | 2041b                      |
| Vanilla wafers                              | 5       | 93  | 1.1  | 3.2  | 14.9 | 8   | 13  | 0.1 | 51  | 15  | 25    | 0.01 | 0.02 | 0.1 | —   | 833b                       |
| <b>Sweets</b>                               |         |     |      |      |      |     |     |     |     |     |       |      |      |     |     |                            |
| Milk chocolate                              | 1 oz    | 147 | 2.2  | 9.2  | 16.1 | 65  | 65  | 0.3 | 27  | 109 | 80    | 0.02 | 0.10 | 0.1 | —   | 587                        |
| *Molasses, jams, jelly, maple syrup         | 1 T     | 52  | 0.1  | —    | 13.4 | 16  | 3   | 0.8 | 2   | 17  | —     | —    | 0.01 | —   | —   | 2050b, 1148e, 1149e, 2049d |
| Soft drinks                                 | 6 fl oz | 72  | —    | —    | 18.5 | —   | —   | —   | —   | —   | —     | —    | —    | —   | —   | 404a                       |
| Sugar                                       | 1 T     | 46  | —    | —    | 11.9 | —   | —   | —   | —   | —   | —     | —    | —    | —   | —   | 2230b                      |

†Approximate values. All values have been rounded to the nearest decimal point.

\*Average value for the group of foods listed.

— Contributes in serving size indicated only trace amount of nutrient.



## AIDS AND DENTAL CARE

The mouth, believe it or not, plays a critical role in the care and promotion of overall good health of persons with AIDS. Dental care — including teeth and gums — can improve a personal sense of well-being, prevent some opportunistic infections, and maintain the ability to eat properly. This brief section is to emphasize the importance of caring for your teeth and encourage you to get regular check-ups and **early** diagnosis and treatment when a problem arises. (Please keep in mind that when you visit your dentist or oral hygienist, the typically high amount of blood exposure requires that gloves are worn and other precautions taken to reduce the risk of AIDS transmission.)

### PREVENTION AND MAINTENANCE

Contact a dentist as soon as you are diagnosed with AIDS. Immediate care and regular check-ups (as recommended by your dentist) can reduce your risk of many opportunistic infections, and use routine oral hygiene rules.

- brush regularly (use a **soft** brush)
- get regular check-ups
- floss regularly
- don't eat too many sweets and rinse or brush soon after

If an infection or lesions are present in the mouth, you may find Toothettes (little sponge-tipped swabs) easier or gentler to use.

### TREATMENT

An aching or diseased mouth can make life very uncomfortable, make it more difficult to eat (thereby affecting nutrition), and make additional infections more likely.

- seek treatment **early**. Problems that continue may be more difficult to treat and lead to complications.
- if you need oral surgery or extensive work, your dentist may prescribe antibiotics to prevent opportunistic infections.
- information regarding infections and treatment should be shared between your dentist and physician to ensure:
  - (1) that prescribed drugs have no conflicting or interfering side effects,
  - (2) that your treatment plan is appropriate,
  - (3) that your overall condition allows for surgery (or other necessary work) at this time.

Dental care is often difficult to obtain for those with AIDS. If you are in need of these services, you might get a referral from your physician, hotline referral service, or local AIDS agency.

## GENERAL HYGIENE MEASURES AND RISK REDUCTION

**Stephen Strigle, B.S., CT (ASCP) and Judith Splegel, M.P.H.**

Good hygiene is important in one's daily living for two reasons. For one, living in a clean environment generally makes you **feel** better and may make your friends and family more comfortable during their visits and glad to return again. Secondly, it is just plain healthy.

There is no question that the use of hygienic self-care practice and living in a clean environment substantially reduce the risk of contracting many infections, not just AIDS; and there is no reason, if you follow the basic principles below that you cannot share your home with others. A few basic rules to follow are: keep your living area at a temperature you can live with, but well-ventilated; keep all areas **clean** — not just neat; and maintain your own cleanliness through daily bathing and dental hygiene. Most importantly, **WASH YOUR HANDS** after using toilet facilities, after contact with body fluids, and before eating or cooking.



## IN THE BATHROOM

- Above all else, **ALWAYS WASH YOUR HANDS** after using toilet facilities
- There is no need for separate toilet facilities, however, it is important to keep them clean. Toilet seats and fixtures should be cleaned routinely with a 1:10 dilution of household bleach. A little full strength bleach can be poured directly into the toilet bowl for disinfection.
- Mop the bathroom floor at least weekly and clean up spills. Again, a 1:10 dilution of bleach (one part bleach to nine parts water) can be used to disinfect the floor and shower stalls. (Athletes foot is caused by a fungus which bleach will kill.)
- Do **not** use the same sponge or washrag for dishes or eating areas which you use to clean up messes that might involve human waste or body fluids.
- It is wise to wear rubber gloves when cleaning bathroom areas or spills on the floor.
- For easier disposal, you might want to use plastic waste basket liners.

## IN THE KITCHEN

- People with AIDS can safely prepare food for others as long as hands are washed before beginning. (It's also a good idea not to lick your fingers while cooking or tasting.)
- Certain foods are best avoided by people with AIDS: Organically grown food (which may be fertilized with human or animal waste) should be cooked if used; organic lettuce is not safe. Unpasteurized milk and milk products have been associated with Salmonella infections in the past, and these infections are not well tolerated by people with AIDS.
- There is no need for separate utensils or dishes, but **all** must be washed in **HOT** soapy water. Use water as hot as you can (you might need gloves); you may want to turn up your water heater. If you are lucky enough to have an automatic dishwasher, use it.
- Do **not** use the same sponge or rag for dishes that you use to clean up floor spills.
- Do not dump water used for mopping up the floor down the sink where food is prepared.
- Clean the inside of the refrigerator with soap and water to control molds, and clean old, stale food from the refrigerator on a timely basis.

## LAUNDRY

- Clothing, bed linens and towels should be washed in a washing machine using **hot** water and household bleach. (Use the dilutions on the product label.)
- Laundry can be dried in an automatic dryer on a hot setting or drip dried in sunlight.
- Clothing or bed linens that are soiled with fecal material, urine, or semen should be washed separately.

## PERSONAL HYGIENE

- Bathing/Washing: Keep your body clean. For persons with AIDS, it might actually reduce the number of infectious agents on the skin which are capable of causing opportunistic infections. Liquid soap dispensers are worth considering (and may be less harsh on the skin), and towels should be your own rather than shared. Perhaps the most important part of bathing or handwashing is **rinsing**. It is this process which actually carries away the germs and dirt.
- Cleansing Enemas/douches: Use a one-time, disposable unit whenever possible. Dispose of units with care, and **NEVER** share equipment. Keep your personal kit clean by boiling the nozzle in hot water after each use. Though considered by some to be a hygienic practice, remember that too much cleansing may be harmful in that it irritates the mucus membranes of the vagina and/or rectum. It may also wash away some of the valuable organisms that keep the system in balance.



- **Dental hygiene:** Although you brush your teeth regularly, the mouth is normally full of germs. A toothbrush should never be shared, whether healthy or otherwise. The gums are fragile and can bleed easily. Other teeth-cleaning devices such as toothpicks, dental floss and water picks should never be shared; there is no danger in sharing the same dental floss **dispenser**. After cleaning your teeth (or dentures), dispose of rinse water properly down the sink. Glasses used to rinse your mouth should be cleaned with **hot** soapy water.
- **Feminine hygiene:** Sanitary napkins and tampons can be potentially infectious and should be disposed of properly (in a lined, protected waste container).
- **Nail hygiene:** Fingernails and toenails are usually dirty, as dirt and organisms get under them. Keep your nails clean and out of your mouth.
- **Secretions:** Despite recent findings that the virus (HTLV III) can be recovered from saliva, epidemiologic evidence argues **against** the transmission of AIDS via saliva or other respiratory secretions. Pneumocystis carinii pneumonia cannot be transmitted to persons with normal immune system function, but it could be transmitted between persons with AIDS. (And of course, other infectious agents can be transmitted between healthy and immune suppressed individuals.) Therefore, persons should be careful to cover their mouths and noses with a tissue when coughing or sneezing. Because of the potentially infectious nature of oral and nasal secretions, **ALWAYS** dispose of tissues properly and wash your hands immediately after exposure to secretions.
- **Shaving:** Razors can harbor minute particles of blood and also irritate the skin. Therefore, **never** share razors.

## **PETS AND THEIR CARE**

- First, we must recommend caution in having pets for individuals with any type of immune deficiency. If you now have, or are considering a pet, consult your physician to determine if any risks exist.
- If you do have a pet, it is essential that you are careful with their waste products and cleaning litter boxes. In fact, persons with AIDS should **not** directly clean animal spills, litter boxes, aquariums or bird cages; ask a friend to help in this matter. Many of the opportunistic organisms are harbored in waste products (whether feces, urine or vomitus).
- Maintain any health needs of your animal, and keep up any shots that are necessary.
- Pets that are exclusively indoor animals and isolated from other animals pose the least risk.

**GENERAL HOUSE CLEANING RULES:** Keep a positive, fun outlook on these activities. As much as you may dislike cleaning, our bet is that you will enjoy your living area much more if it's clean, and you will feel healthier!

## **HOME CARE**

**Jennifer Lang, R.N., M.N.**

Because of personal preferences and the difficulty placing persons with AIDS in skilled nursing facilities, many patients with AIDS who are too sick to care for themselves are cared for in the home by professionals, friends or family members. The following guidelines, along with the general hygiene measures in the previous section, should be helpful in providing home care.

**Hygiene:** In the person with fevers and night sweats bathing becomes not only a hygienic necessity but also a refreshing relief. For the person who has enough strength to



get out of bed but not enough to stand alone in the shower, placing a stool or chair in the shower stall or bathtub is helpful. The use of a shower-hose attachment to the faucet cuts down on spray considerably. Getting in and out of the bathtub may be difficult for someone with weak leg muscles; therefore a chair in a shower stall is probably easier.

If unable to get out of bed, a daily bed bath can be accomplished with the use of a basin of lukewarm water, a face cloth, bath towel and mild soap. Remove the bed covers, the patient's pajamas and cover the patient with a sheet, large towel or light blanket to prevent chilling. Wrap the face cloth around your hand to form a mitten and wash the face first. Avoid soap on the face since it is hard to remove if it gets in the eyes. Wash, rinse, and pat dry with the towel. Wash hands and arms next — first with soapy wash cloth, then rinse and wipe soap off, then pat dry. Wash and dry each arm separately to avoid chilling. The front of the chest and neck comes next, followed by the abdomen, back, buttocks and genitalia. Feet and legs go last. If the water gets too soapy, dirty, or cold, change for fresh water. Bath water should be lukewarm (104° F). Wear rubber gloves while bathing the patient, particularly when washing the rectal or genital area. This is particularly important if there is any fecal soiling. The application of lotion especially to feet and elbows not only refreshes but also protects the skin from sheet friction.

**Oral Hygiene:** Daily mouth care is very important. If thrush is present more frequent care (every 4 hours) is required. If toothbrush bristles cause discomfort or bleeding, use a face cloth, or commercially available "Toothettes" (popsicle sticks with foam rubber attached) to clean teeth and gums. Mouth rinses with warm salt water (¼ tsp per 8 oz. glass of water) are helpful. Hydrogen peroxide in a 50:50 dilution with warm water can also be used. If your patient cannot cooperate with mouth care, the mouth can be kept open by placing a wooden tongue depressor (blade vertical) between upper and lower teeth while cleaning is accomplished. The patient who cannot cooperate may also be confused and capable of choking. In such a case do not use mouth rinses.

**Shaving:** The use of an electric razor is recommended as the risk of bleeding increases with a regular blade razor. If a regular razor is used, the caregiver should wear disposable rubber gloves while shaving the patient.

**Changing Bed Linens:** Ideally, the patient will be strong enough to get out of bed while the bed linen is changed. If not, remove the top linen, have the patient turn on his side to one side of the bed, roll the dirty sheet like a sausage and push it as far as possible under the patient's back. Fit the clean sheet onto the empty side of the bed and fold the loose (untucked) portion of the clean sheet in an accordion fashion close to the patient. Then, you can roll the patient onto the fresh sheet; remove the old linen; and lastly, tuck in the remaining portion of the clean sheet neatly under the mattress. Apply a clean top sheet and blankets if needed. Bed linen that is not soiled does not need to be changed daily, but a fresh, unwrinkled bottom sheet does improve comfort. For the patient who has difficulty controlling urination or bowel movements, the use of disposable plastic lined underpads may protect linen and mattress from frequent soiling. These are commonly called "Chux" and can be purchased at drugstores or hospital equipment rental stores.

There are several advantages to using a rented hospital bed. The mattresses are covered and easily cleaned. Since most of them are electric, they can be raised to a high position while changing linens to protect the caregiver's back and then lowered for the patient's safety. The head and knee sections can also be raised and lowered to vary comfort and feeding positions for the patient. When prescribed by the physician, most insurance plans will cover the expense.

**Meeting Nature's Demands:** Whenever possible the patient should be encouraged to use the bathroom — if for no other reason than to provide some exercise and promote a sense of independence. If this is not possible, then a urinal or bedside commode are



possible substitutes. A bedpan, although difficult to use and also uncomfortable, may be a necessity for the patient who is not able to get out of bed. The use of underpads will protect bed linen in this case. For the patient who is not able to control bladder function, a condom catheter (described in supply section) will prevent bed-wetting.

## **Useful Supplies and Equipment for the Home Care of the AIDS Patient**

Almost all of the items listed below can be purchased or rented from either a drugstore or a hospital equipment establishment. When prescribed by the physician, many insurance plans will cover the expenses.

1. Disposable latex or vinyl gloves. They don't need to be sterile. Most come in boxes of 50 for approximately \$14.00
2. Disposable plastic-backed underpads to protect sheets from fecal or urinary soiling. Known as "Chux", they come in several sizes and quantities. The largest size is most useful.
3. Disposable face masks.
4. Plastic urinal, reusable.
5. Bedpan or bedside commode. A commode is helpful for the patient who can get out of bed but is not strong enough to get to the bathroom.
6. A Texas catheter, also known as a condom catheter, is a rubber sleeve which slips over the penis. A drainage tube which goes to a collection bag is attached to one end of the condom. This is helpful for the patient who is having difficulty controlling urination.
7. Hospital beds are particularly helpful for the AIDS patient who is not very mobile since the bed height can be raised to protect the caregiver's back or lowered for the patient's safety. In addition, the head of the bed can be raised to facilitate eating or breathing.
8. Wheelchair: A collapsible wheelchair with brakes and a footrest which will fit easily into a car is a useful addition particularly for getting from hospital parking lots to clinics.
9. Walker: A four-legged aluminum frame which the patient moves in front of him is helpful for the patient who is still mobile but has problems maintaining balance.

## **Precautions for Care Givers**

1. Wash hands before and after direct contact with the patient.
2. Wear disposable rubber gloves when:
  - a) Bathing or cleansing the rectal or genital area
  - b) Giving mouth care
  - c) Emptying a bedpan or commode
  - d) Shaving with a safety razor
  - e) Giving injections
  - f) Cleaning up vomitus, urine, or stool.
  - g) Cleaning toilet fixtures
3. Wear an apron which protects clothing from shoulders to knees whenever giving care which may place you at risk of being soiled from fecal material, vomitus or urine.
4. Wear a face mask only when coming in close contact (within 3 feet) of a patient who is coughing sputum into the air.
5. Dispose of soiled plastic or paper items in a plastic garbage bag.
6. Wash aprons in hot water with detergents and household bleach.



7. Dispose of urine, stool and vomitus in the toilet.
8. Clean commodes and toilet fixtures with any disinfectant. A 1:10 dilution of household bleach is cheapest and effective.
9. The toilet brush used to clean toilet bowls or commodes should soak in a diluted bleach solution between uses.
10. Needles and syringes used to withdraw blood or give injections in the home should be saved for disposal in a small used coffee can, lined with a plastic bag and covered with a plastic top. When the coffee can is full, make sure the plastic bag is **inside** the can and then place in a 350-450 degree oven until the plastic syringes have melted. Allow the can to cool, remove from the oven, cover with plastic lid and dispose of in the trash.

## **SYMPTOM MANAGEMENT**

### **Pneumocystis carinii Pneumonia (PCP)**

#### **What to watch for:**

- a. Shortness of breath under circumstances which would not normally make you short of breath.
- b. Dry cough.
- c. Unexplained fevers higher than 101 degrees, for more than 24 hours.

#### **What to do:**

- a. Record your temperature with a thermometer every 4 hours.
- b. Drink plenty of fluids.
- c. Call your doctor if the symptoms become worse or fail to improve over one or two days.

#### **What information to give your doctor or nurse:**

- a. Duration of shortness of breath in days or weeks. Is it getting worse, better, or staying the same. What makes it worse? Better?
- b. Duration of cough. Are you producing any phlegm (sputum)? If so, what color, how much, and when?
- c. What has your temperature been for the past 24 hours? What have you done or taken for it? Have these measures helped?

#### **What to expect:**

What your doctor decides to do will depend on how serious he thinks the problem is. He may choose to:

- a. Wait for further developments and keep in touch with you by phone.
- b. Order a chest x-ray.
- c. Admit you to a hospital for further evaluation.

#### **If you are admitted to the hospital, you might expect:**

- a. Further chest x-rays.
- b. A bronchoscopy — insertion of a flexible tube into the bronchial tube to obtain a lung tissue biopsy for *Pneumocystis carinii*. Besides an open lung biopsy, this is the only way to make a definite diagnosis of PCP.
- c. Arterial blood gases — removal of a small amount of blood from an artery in the wrist or the groin in order to determine how well your blood is oxygenated.

#### **If you do have PCP, you can expect:**

- a. To have oxygen administered through your nose if the blood gases indicate a low oxygen level, or if you are short of breath.
- b. To receive one of two antibiotics — either trimethoprim sulfasoxazole, a sulfa drug; or pentamidine, a drug obtained from the Centers for Disease Control.
- c. Frequent chest x-rays.



**Your responsibilities as a patient are:**

- a. Communicate fears, needs and concerns to staff. They care about you and want to help so that they can best meet your needs.
- b. Understand what is happening to you, what is planned, and what the treatment goals are.
- c. Continue to take your medicine after discharge from the hospital. PCP has a high recurrence rate, therefore prevention is essential. Unfortunately, the sulfa drugs Bactrim and Septra have a high rate of reactions. If you develop a rash and/or fever while on either of these medications, call your doctor.

**Oral Candida (Thrush)****What to watch for:**

- a. Soreness of mouth or tongue, a "burnt" feeling.
- b. Pain or difficulty swallowing.
- c. Appearance of white patches on tongue or back of mouth which do not come off with a toothbrush.

**What to do:**

- a. Make an appointment to be seen by your doctor. Unless this problem entirely prevents you from eating, it is not an emergency and can wait a few days for treatment.
- b. While waiting for an appointment, you can rinse your mouth with a warm salt water solution (about 1/4 teaspoon salt per 8 ounce glass) every 2-3 hours.

**What to expect:**

If your doctor thinks that it is candida, you may get a prescription for either Mycostatin® suspension or Ketoconazole® tablets. It is essential that you take the medication as directed, or it will not work. Do not skip doses!

**Your responsibilities:**

Consult your doctor if the problem has not resolved after 2 weeks of medication.

**Weight Loss****What to watch for:**

Unexplained weight loss of more than 10 pounds in a month and which cannot be regained. (In AIDS, weight loss commonly occurs without reason and despite good appetite.)

**What to do:**

- a. Weigh yourself without clothes or shoes no more than once a week, and keep a record. Weigh yourself at about the same time of the day.
- b. Keep a food intake diary to determine calorie intake whenever you think you are losing weight. (See the Nutrition section of this manual for more information.)
- c. Try to eat a diet well balanced in fats, proteins and carbohydrates.
- d. If you are losing weight, maintain intake at a minimum of 20 calories per pound of ideal body weight (see nutrition section for specifics on how to determine this). You can do this by using sauces, gravies, Sustacal, Carnation Instant Breakfast, and other liquid nutrients.
- e. If three large meals a day is difficult, split your total daily intake into six smaller meals.
- f. If you continue to lose weight, call your doctor.



**What information to give:**

- a. How many pounds lost over what period of time.
- b. Approximately how many calories you consume each day.

| DAY | Weight (lbs.) | Foods Eaten |
|-----|---------------|-------------|
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |
|     |               |             |

**What to expect:**

If your weight loss has been excessive (more than 20 pounds in one month), you may be admitted to the hospital for evaluation and perhaps intravenous feedings.

**Your responsibilities include:**

- a. Eat even when you are not hungry.
- b. Explore new ways of meeting nutritional needs.
- c. If you do not feel well enough to cook for yourself and no one else is available, ask your local AIDS organization for assistance in making arrangements to get help.

**Diarrhea**

AIDS patients are particularly prone to intestinal parasites such as amoeba, giardia and cryptosporidia. There are treatments available for amoeba and giardia, but not for cryptosporidia. Diarrhea may also occur without an identifiable cause.

**What to watch for:**

- a. More than six loose stools per day.
- b. Watery, mucoid or bloody stools.
- c. If bloody stools, does blood come before, with or after the bowel movement.
- d. Approximate volume of bowel movements.

**What to do:**

- a. Call your doctor and describe your stools; a stool specimen for parasites or bacterial culture may be required. Get stool containers from a hospital laboratory. If your doctor is concerned about cryptosporidia, a special container containing a preservative can be obtained. Stool specimens are more easily obtained if plastic wrap is placed across the toilet bowl to prevent the stool from falling into the toilet water.
- b. If stool cultures are negative but diarrhea persists, try altering your diet — avoid dairy products, spices, coffee, alcohol, and foods high in fat. Drink liquids at room temperature. Avoid fresh fruits and juices high in acid.



**What to expect:**

- a. If stools contain amoeba or giardia, you may be given a prescription for Flagyl. Medication that is not completed is not effective; take the entire regimen as directed. Alcohol intake while taking Flagyl may cause an adverse reaction.
- b. Drugs that delay transit time from food ingestion to elimination may be prescribed (i.e. Lomotil).
- c. There is no known treatment which will eliminate cryptosporidia, but medications can be prescribed which reduce discomfort.

**Your responsibilities as a patient:**

- a. Take medication as prescribed.
- b. Avoid alcohol intake while taking Flagyl.
- c. Maintain fluid intake (non-caffeinated) to prevent dehydration. (Chipped ice or popsicles may be easier to tolerate if diarrhea persists.)
- d. Report symptoms of weakness, dizziness or excessive weight loss.

**Dehydration**

(Excessive loss of body water due to fevers, sweating, diarrhea or decreased fluid intake.)

**What to watch for:**

- a. Dryness of oral mucus membranes and tongue.
- b. Skin on back of hand which when pinched (into tent shape), does not return to its place quickly.
- c. The passage of very little (less than 1 cup) or no concentrated urine over a 12 hour period. (Concentrated urine is dark yellow in color.)
- d. Inability to take in as much fluid as is being lost in diarrheal stools.
- e. Confusion — difficulty remembering where you are or behavior that is strange for you.
- f. Dizziness when standing.

**What to do:**

- a. Control fevers as advised by your physician.
- b. Increase fluid intake with water, juices, Gatorade, popsicles, ice, etc.
- c. Measure the amount of urine passed.
- d. Call your physician if you start feeling more confused, cannot increase your urine output to at least a quart every 12 hours by increasing fluid intake, are having difficulty taking in enough liquids.

**What information to give:**

- a. Temperature for past 24 hours.
- b. Approximate amount of fluids taken in for past 48 hours.
- c. Approximate amount of urine passed in past 24 hours.
- d. The presence and/or severity of diarrhea.
- e. Your weight today and comparison to what it was a week ago.

**What to expect:**

If your doctor does not think you can manage this at home, he may admit you to the hospital to give intravenous fluids.

**Your responsibilities as a patient:**

- a. Maintain a fluid intake which is at least a quart more than your combined urine and stool output.
- b. Be alert for signs of dehydration.
- c. Report any concerns to your physician.

**Fevers**

(Usually fevers are a sign of infection, but AIDS is often accompanied by night-time fevers and sweats for which no cause can be found.)



**What to watch for:**

- a. Temperatures greater than 101 degrees.
- b. The time of day they occur.
- c. Night sweats which soak through bed clothes and sheets.
- d. Other signs of infection (sore throat, headache, cough, etc.)

**What to do:**

- a. Record temperature every 4 hours (no more often) for two to three days, and look for a pattern.
- b. Discuss findings with your doctor — call sooner if other symptoms coincide with fevers.
- c. Drink plenty of fluids to replace the water you lose through sweating.
- d. Ask your doctor whether he/she prefers aspirin or Tylenol, and the preferred method for taking the medication.

**What to expect:**

- a. If your doctor suspects an infection, he may want to evaluate with blood or urine cultures, x-rays, etc.
- b. If no cause is found and the fevers are related to AIDS, you can expect them to recur episodically and last for several days at a time.

**Your responsibilities as a patient:**

- a. Rest when you are tired.
- b. Consult with your doctor as to the best approach to take when fevers occur.
- c. Maintain fluid intake to compensate for fluid loss through night sweats and increased metabolism. Gatorade may be helpful for restoring electrolyte balance.

**Fatigue**

(This is a common symptom with AIDS which may interfere with lifestyle, and either last for an indefinite period or occur in cycles.)

**Your responsibilities as a patient:**

- a. Consult with your physician if fatigue prevents you from working or caring for yourself, becomes significantly worse, or is associated with cough, shortness of breath, or a new fever.
- b. Maintain an exercise program which does not cause excessive fatigue but helps maintain muscle mass.
- c. Inquire about eligibility for disability (financial assistance) if fatigue prevents you from working.

**Changes in Mood, Personality, Behavior, Speech, or Memory**

(The opportunistic infections which affect the brain or central nervous system may develop slowly and are accompanied by subtle changes in personality or speech. Close friends or lovers are often the first to recognize these.)

**What to watch for:**

- a. Changes in the way you respond to situations — i.e. anger for no reason, suspicions of others' behavior, desire to be alone (if new for you), difficulty coping with things that are not normally a problem.
- b. Difficulty understanding or forming words.
- c. Difficulty with balance or ability to walk; new weakness of an arm, leg, hand or foot.
- d. Severe headaches or neck stiffness.
- e. Changes in the way close associates react to you.
- f. Difficulty remembering where you are or recalling important events.

**What to do:**

- a. Ask those who know you well if they have noticed any changes in your behavior.
- b. Discuss any concerns with your physician(s).
- c. Don't allow yourself to think that you are going crazy!



### What to expect:

If your physician thinks your concerns may be valid, he may:

- a. Hospitalize you to evaluate for opportunistic infection.
- b. Allow you to stay home while he evaluates your symptoms further.
- c. Recommend that you have someone stay with you to help if needed.

## MANAGING THE SIDE EFFECTS OF TREATMENT FOR KAPOSI'S SARCOMA

Jennifer Lang, R.N., M.N.

Management of many of the treatment side effects are similar to those already described in the symptom management section. Additional information can be obtained from that section.

**Nausea** may occur as a side effect of any of the treatment programs, is usually transient, and lasts for a few hours after treatment. Nausea and vomiting as a result of chemotherapy respond better to **preventive** approaches; once vomiting starts, it is difficult to stop until it runs its course. Avoiding food intake prior to therapy may help. Your physician or chemotherapy nurse will be able to help you find the best method of dealing with the problem and prescribe anti-nausea medications when indicated.

**Diarrhea** may occur following radiation to the abdomen or some chemotherapy treatments. Radiation associated diarrhea results from inflammation of the lining of the intestines and may be controlled with a low fiber, lactose-free diet, or with medications to slow down intestinal motility. Diarrhea following chemotherapy will usually run its course over a few hours and requires no treatment unless it persists.

**Constipation** may occur as a side effect of vincristine or vinblastine and occurs several days **after** therapy. Usually this can be prevented with a high fiber diet and high liquid intake. If abdominal cramping occurs in the absence of a bowel movement for more than three days, consult a physician.

**Mouth Sores** occur due to loss of the upper most layer of cells covering the mucus membranes. This can occur several days after treatment (chemotherapy or interferon) and lasts until new cells grow (approximately seven days). Rinsing the mouth frequently with warm salt water is most helpful. Use a **soft** toothbrush or toothettes (a sponge tipped stick) to clean teeth. A medication called viscous xylocaine can be prescribed to reduce mouth pain, but the results are temporary and of short duration.

**Hair loss** occurs as a result of chemotherapy. Interferon can cause a thinning of hair, but generally not a total loss. The severity of hair loss as a result of chemotherapy varies from drug to drug. With vinblastine it may be minor; with adriamycin, major. Hair fall-out usually begins 7 to 14 days following treatment and some new growth may be evident just prior to the next treatment. Following completion of chemotherapy, hair will return completely, but sometimes with a different color or texture. In recent years a technique which involves cooling the scalp with ice packs to reduce the amount of chemotherapy reaching the hair follicles has been found to delay hair loss in some situations. Given the fact that Kaposi's Sarcoma is a skin tumor, scalp cooling is **not** recommended.

**Lowered Blood Counts** occur as a result of the effect of treatment on the bone marrow. The bone marrow is responsible for producing white blood cells, platelets, and red blood cells. The bone marrow responsible for producing the majority of blood cells is found in the ribs, sternum (breast bone), hips, vertebral column (back bone), skull and upper arms. Radiation therapy which involves any of these areas will affect blood counts. Some



Chemotherapy drugs have more of an effect on blood counts than others. Interferon also may have an effect. Chemotherapy affects blood counts by temporarily arresting the ability of the bone marrow to produce new blood cells. White blood cells and platelets are especially sensitive to this effect and usually reach their lowest level 7 to 14 days after treatment. Chemotherapy treatments are usually spaced to allow time for the bone marrow to recover prior to the next treatment. When counts are at their lowest level, patients are particularly at risk of developing infections, bruising, or bleeding easily from cuts. The appearance of new symptoms of fever or easy bruising should alert chemotherapy patients to the possibility of low counts which need evaluation. Crowds and activities that involve vigorous physical contact should be avoided during this time.

**Fevers:** Patients receiving bleomycin or interferon may experience fevers, chills, muscle aches or pains within a few hours of treatment. These are expected side effects and can be minimized with medications such as Tylenol and antihistamines (for bleomycin) when indicated.

**Numbness and tingling of fingers** are temporary toxic side effects of vinblastine or vincristine and should be reported to the physician at the next appointment so that subsequent doses of chemotherapy can be reduced.

**Impotence:** Some chemotherapy agents (vincristine and vinblastine) may temporarily interfere with the ability to achieve an erection. This will resolve spontaneously following discontinuance of these drugs.

## SECTION V

### PSYCHOSOCIAL ASPECTS OF AIDS

- Meeting Psychological Needs in the AIDS Crisis
- Sexual Expression and Risk Reduction
- Stress: Its Cause and Control
- AIDS as a Terminal Illness

### MEETING PSYCHOLOGICAL NEEDS IN THE AIDS CRISIS

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Stephen F. Morin, Kenneth A. Charles, and Alan K. Malyon; "AIDS: The Psychological Impact on Gay Men" *American Psychologist*, 1984 in press.

Stephen Morin and Walter F. Batchelor, "Responding to the Psychological Crisis of AIDS," *Public Health Reports*, 1984 in press.

David Epstein's contribution was written specifically for this manual.



AIDS impacts all who come in contact with it. Whether you are the diagnosed person, family, friend, or care provider, you cannot help but be touched by its widespread implications. This chapter provides an overview of some emotional and mental concerns arising from AIDS, and it may be of particular interest and help to loved ones and those caring for people with AIDS. We have included potential solutions and available resources that might enable you to cope with the AIDS crisis and promote your well-being. If you would like to pursue further resources, contact your local AIDS organization (listed in the Appendix).

Lovers of persons with AIDS may have their own needs for psychological care. There may be fears relating to their own health risks and the stress of providing support to their diagnosed lover. Knowing that one has shared the most intimate contact with another who is dying of a contagious disease can be shattering, and the extent of knowledge about AIDS is such that medical evidence cannot fully dispel these fears. (It does not appear, however, that most lovers of people with AIDS have developed the syndrome.) Lovers are almost certain to face many of the same situations as those diagnosed as they help with daily tasks through the duration of their lover's condition.

When individuals are diagnosed with AIDS, their friends are faced with a series of distressing issues. Gay friends may be particularly vulnerable because they can readily identify with those diagnosed. Indeed, friends often *over-identify* and act as if *they* have just been diagnosed. Other reactions might include awkwardness in discussing the illness and problems in working through fears they have regarding contagion. Some of these people may want to be supportive but not know how to be so. For many, the diagnosis of a friend leads to difficult reappraisals and evaluations of their *own* lifestyle and learning new behaviors.

Issues of bereavement may also be difficult for both friends and family. Since most persons with AIDS are fairly young, their lovers, friends and family may not be as equipped to deal with the issues of death as in older people. There may also be a sense of injustice because of the "untimeliness" or "undeserved" nature of the illness.

For the first time in my life, October 1981, I found myself bedridden with a cold that wouldn't go away, viral bronchitis, fever, diarrhea, loss of appetite, and extreme fatigue. These problems persisted for several months and were coupled with the discovery of swollen lymph nodes, which really began to alarm me. Then I developed chronic ear infections, shingles on the backs of both legs, and a persistent sore throat. The diarrhea continued and nausea became a fact of everyday life; eating became increasingly difficult — I began to lose weight.

I was frightened and depressed by the fact that the illnesses were multiple, and that no sooner would one go away than something else would appear. I then began to experience with increasing frequency the most alarming and intimidating of all these maladies — night sweats. Sometimes I would wake up crying because I was so cold and frightened. No amount of preparation before bed could relieve the anxiety and fear of what was to come. I dreaded what I knew I needed most — sleep; I didn't want to close my eyes.

The initial diagnostic process was probably as confusing and frustrating to the doctors as it was to me. Blood tests and biopsies were always negative or inconclusive; the doctors could only tell me what I didn't have. "Well, it looks like Hodgkin's Disease, but it isn't — and it looks like leukemia, but it isn't" etc.

They ruled out the likely and even the unlikely possibilities. I still didn't know. Nothing. I had no idea if it was contagious, if it was curable, if anyone else had it or had ever had it. I was alone, frightened and confused. I desperately needed help in coping with the emotional turmoil of facing this unknown.

— thoughts of a person with AIDS  
(Morin and Batchelor, 1984)



Mental health considerations should be a part of **all** assessment and treatments procedures for people with AIDS. Psychological support at the point of diagnosis, for instance, can help prevent natural fear and anger from being transformed into self-destructive expressions. Involvement during continuing medical treatment can help develop understanding of the emotional needs of both patient and health professional. Involvement during the stages close to death can bring a depth of caring that supercedes the depression and fear at hand.

The psychological needs of the person with AIDS are similar to those of the cancer patient. Almost always, the human response to a life-threatening illness is profound stress and despair. The primary aim of psychotherapeutic intervention, therefore, is most often that of **enhancing coping abilities and providing emotional support**. Counsel with a health care provider assists in coping with the many needs of the crisis. Providing emotional support lies with the family and friends of the person with AIDS.

The attitude of mental health professionals toward homosexuality is important. Too frequently, psychotherapy has been characterized by a heterosexual bias, i.e. a belief that heterosexual orientation is better or more natural than a homosexual orientation. This heterosexual bias is reflected in diagnostic assessments, treatment goals, and even the language used in psychotherapy. The fact that a significant percentage of gay men do not feel emotionally supported by their families and may be isolated from other gay men and women makes it imperative that health care professionals look for, identify, and respond to the special psychological needs. It is important to support the individual's gay identity, not deny it.

Learning for the first time that a friend or family member is gay can cause additional stress, making it difficult to cope with an already trying and often complicating bereavement. For some, diagnosis of AIDS is an automatic identifier as homosexual. Families that do not accept the homosexual orientation of an individual may find it particularly difficult to be supportive during the duration of the AIDS experience. Furthermore, the social stigma associated with the diagnosis involves a **presumption** and sometimes judgment about an individual's lifestyle, and there may be a fear — on the part of those diagnosed or family — of being "found out" by the general community. Certainly, these complexities are not experienced by all.

**Editor's note:** For information on how to cope with a loved one's homosexuality, refer to the Resources Section in the Appendix. The organization Parents and Friends of Lesbians and Gays (FLAG) deals specifically with this issue.

Therapists likewise need to be understanding and empathetic of the individual's awareness and reactions. It can be a very frustrating experience for a clinician to see a client engaged in life-threatening activities. As one colleague said, "It's very difficult to be understanding of people engaged in such gross denial. What I really want to do is rant and rave and lecture." As difficult as it is to be empathetic in these situations, it is imperative to do so, as moving too quickly with clients who are not ready to face the realities of AIDS can alienate them, thereby losing the opportunity to intervene later.

The critical psychotherapeutic issue in helping persons with AIDS is **reducing anxiety and its attendant physical stresses**. It has recently been hypothesized that psychological distress may contribute to immune suppression (Coates, Temoshok and Mandel, 1984). Biofeedback, relaxation training, hypnosis, and many other techniques have been shown to lower levels of stress. Therefore, it may be that stress reduction techniques might contribute to a reversal of immune suppression in some people. This is clearly an area that deserves immediate and comprehensive research attention. (See stress reduction section and Appendix in this manual.)



## SEXUALITY

I used to encourage gay clients to go out to the baths who've never been to the baths, I've encouraged clients to go out to a bar and pick up people, to try out, explore, and experiment with lots of different aspects of their sexuality because I think that's one of the most wonderful, positive aspects of the gay subculture. Now with AIDS, I'm needing to do the opposite. With clients who are continuing to do those things, I feel a real ethical responsibility to bring up my concern. I have clients who are still going to the baths and that concerns me. I point out the information and point out my personal concern for them. If I care about my clients, which I do, I just can't sit there and in a kind of cold, analytic fashion say what they do is up to them. So, I've been working a lot with AIDS-safe sex.

— comments by one sex therapist

Currently, psychologists are trying to maintain a delicate balance, that is, to remain sex positive and gay affirmative while at the same time working towards an educational model of safe sex (no exchange of semen or blood-related secretions). A number of therapists have reported marked increase in the amount of time they spend helping clients to set and maintain sexual limits. Many clients also need assistance in assertiveness and social skills in order to be able to negotiate these sexual limits with their partners. Some people use sex to reduce anxiety. For these people, the added ingredient of having to remain assertively conscious may dilute the anxiety reducing effect, and in turn, cause considerable resistance to the safe sex techniques.

Many mental health professionals are seeing clients who present the complaint of compulsive sexuality. Some people are still having anonymous sex with numerous partners, and afterwards suffer from panic attacks, fear and guilt. Clients with this presenting complaint may be assisted by the techniques ordinarily employed for other compulsive problems. Groups such as Sex and Love Anonymous, modeled after Alcoholics Anonymous, Narcotics Anonymous, Overeaters Anonymous, etc., have proven to be effective.

## INTIMACY

Another major therapeutic issue highlighted by AIDS is intimacy. Intimate relationships fulfill basic human desires for love and affection. Relationships can also answer sexual needs and be a haven from the fears, anxieties, and general complications of the AIDS crisis. The current health crisis has created an atmosphere where the gay community is placing more emphasis and more peer pressure on men to couple. For those previously not having been in a relationship, this involves, among other things, learning a new set of skills. These are primarily the skills of cooperative living. For some, becoming part of a couple requires a working through of fears of intimacy and other issues as well.

Naturally, some men have a history of being in intimate relationships but are not currently in them; they generally evidence confusion and frustration about finding an appropriate partner. Whereas some of the men in this category have, in the past tended to make most social contacts solely through bars and baths, many are beginning to explore new ways to meet people. The larger and better organized the gay community is in a particular city, the greater is the opportunity to find already established special interests groups such as hiking clubs, athletic clubs, literary discussion groups, etc. These interests and activities often provide opportunities to meet a partner.

A third group concerned with intimacy, those already in relationships, may also have difficulties. For some, sex outside of the primary relationship was used by one or both partners to alleviate pressure or sexual boredom within the relationship or to lessen external pressures, helping to keep these outside of the relationship — both, perhaps, in the service of increasing shared intimacy. The closing of open relationships sometimes creates difficult expectations; the relationship alone is now expected to meet many needs previously satisfied elsewhere.



## PROVIDING EMOTIONAL SUPPORT

Just as professional help in coping skills is needed, support is needed on a more personal level. This kind of help best comes from families, friends, lovers, and spouses. Most importantly, perhaps, emotional support can come from fellow persons with AIDS.

Support groups have become an intrinsic part of the treatment of people with AIDS. Knowing that others face similar problems, fear similar fears, and share similar joys is comforting to each of us; but this is especially necessary for individuals who are isolated from society as are many people with AIDS.

Frequently, those newly diagnosed express initial hesitation about joining a support group. This is understandable since going to one of these groups can be a frightening experience. Attending the group means one accepts the diagnosis and is willing to confront in the words, faces, and physical conditions of the other group members what the future may bring.

Although I wanted to be there, it was just too much for me. I had to leave. One of the men was so weak, he couldn't even walk in without help. He had lesions of his face, his hands. His hair was almost all gone from the chemotherapy. He was only thirty-one years old. It was just too graphic. Is this what I was going to look like soon? I just couldn't take it.

Support groups provide an opportunity for those people who have been diagnosed with AIDS to discuss their varied reactions in a safe atmosphere with people who truly understand, at a feeling level, as they share their experience. With time trust builds, friendships form, and people can begin to move to a point of acceptance of their diagnosis and illness. Physical contact in these support groups is of great importance to people with AIDS who may not be getting much physical comfort elsewhere due to people's unjustified and ill-informed fears of casual contagion. Groups also help people express their anger and resentment as a result of having lost friends, lovers, homes, and being asked to leave bars, restaurants, and even juries. Group discussions may center around any of the following: medical information, decisions and treatment, financial planning, disability applications, discriminatory treatment, and needs for supportive physical contact. Role models for dealing with adversity often emerge.

Support groups can provide a safe and useful mechanism for friends, family, and lovers of people with AIDS to share their experiences as well. While not directly afflicted with AIDS, these individuals may share many of the same concerns and fears of the individual who actually has AIDS. Topics discussed might include: fear of contagion, fear of death or grieving, reduced or altered social life, health concerns, or obsessional thoughts about AIDS.

### AIDS PROJECT/LOS ANGELES SUPPORT GROUPS

David Epstein, Ph.D.

Within APLA's support groups for persons with AIDS, we encourage members to live with AIDS by encouraging them to find and/or develop new meaning in their lives, to accept support or help while trying to maintain a sense of mastery or control over their lives, and to strive toward self-enhancement.

Often when persons are confronted with the possibility of their death, the meaning of and in their lives becomes a focus of attention. Whether one believes that he or she has forty years or four months to live, we encourage members to find value in life in the present. For one group member, meaning has developed into truly enjoying his friends and family, while for another it has developed into a strong spiritual sense of self, while for a third it has come from accepting himself and his homosexuality.



Group members are encouraged to discuss their medical treatment and are supported in their efforts to cope with the illness by consulting physicians, psychotherapists, nutritionists, and other health care professionals.

Some members find it helpful to "mentally fight" the illness through visual imagery in addition to working with health care professionals (see Simonton, Simonton and Simonton, 1978). Exercises in relaxation and stress reduction are encouraged.

As noted earlier, AIDS can psychologically wear someone down. Group members, therefore, are encouraged in the present to nurture themselves or to do things which will bring joy to life. Many group members who have had to deny themselves a great deal or who have suffered losses in several areas of their lives report having faith in themselves and their own inner resources. Several members have allowed themselves to finally do positive things for themselves which they had put off for years prior to their diagnosis of AIDS. All group members are actively encouraged to support one another in not succumbing to guilt or self-blame. Some group members have found comfort in the book **When Bad Things Happen to Good People** (Kushner, 1981).

AIDS Project/Los Angeles offers several support groups, each oriented toward a different need. The Project offers groups for people with AIDS, couples groups which involve the partners, lovers or families of persons with AIDS, and bereavement groups. Other local AIDS-related organizations may also have similar groups. Don't be afraid to check them out. AIDS is a difficult life situation for **all** involved, from the individual diagnosed with AIDS to the health care professional caring for him or her.

To conclude, it is understandable that those diagnosed with AIDS — and even those who are not — experience tremendous distress and frustration as a result of the syndrome. It is important to seek and accept support from those who care and share your concerns. There **are** people who will listen, be available physically and to socialize, to share, and to survive this time of crisis.

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## EXPRESSIONS OF SEXUALITY AND RISK REDUCTION

Rex Reece, Ph.D.

### General Purposes of Sex

Sex satisfies a combination of physical and emotional needs — different needs for different people at different times. Among other things, sexual desire may include a need for physical release, emotional expression and intimacy, reassurance of being loved or of being desirable. Sex can also be a way of passing time, the result of habit or an escape from any number of uncomfortable feelings. For a person with AIDS, physical intimacy — a term that includes warm sex (expressions of affection and pleasure such as touching, holding, stroking, caressing and endearing comments) and/or hot sex (passion, lust, physical arousal and perhaps orgasm) — can continue to be an expression of the feelings and needs that have always been a part of his/her sexuality. Bear in mind that just as personal motivations for sex are based on a variety of needs, the means to respond may be equally varied. Finding alternate activities to meet these needs can be helpful.



## AIDS' Effect on Sexual Desire and Response

Physical illness can alter one's needs for sex. Health problems may contribute to one's feelings of loneliness and isolation and, therefore, increase the need for reassurances of love and care from others. AIDS sometimes causes visible physical changes that can make a person with AIDS feel less sexually desirable. Some people with AIDS may become more physically dependent as a result of their illness, and consequently may feel unneeded or burdensome. Physical intimacy can help combat these and other uncomfortable feelings for someone with AIDS. Sex can reassure a person with AIDS that it is still possible to give pleasure to another person, or perhaps, more importantly, to **receive** pleasure.

Illness can make **anyone** less interested in sex and sometimes less physically responsive. When one does not feel well, whether physically or emotionally, it is not unusual to be less interested in sex. Certainly, many medications affect sexual interest and response. Furthermore, because AIDS has some association with sexual activity, a person with AIDS may be less interested in sex because of anger, guilt, frustration or fear involved in that association. The risk of transmission to others or one's increased vulnerability to other infections may significantly inhibit one's sexual desire or activity. Even when the desire is there, the physical response may be altered. Physical stamina may be lessened so that one has limited energy; sexual sessions may be somewhat shorter or less active than pre-illness. Men may experience less frequent erections or have difficulty maintaining them. Lubrication may not be as abundant or orgasms may not be as readily forthcoming.

## Health Conscious Sex

Since it is likely that AIDS is transmitted through the exchange of bodily fluids such as blood and semen during sex, the level of risk involved in specific sex acts is important to consider. For a person with AIDS, the greatest risk in sexual expression is the possibility of getting some additional infection from a partner. Similarly, the partner is at risk of contracting AIDS.

Avoiding the exchange of blood and semen during sex assures lower risk of transmission. Since the risk of transmission through urine, feces and saliva is still being debated by physicians, health conscious sex includes not exposing oneself to the exchange of these substances as well.

It seems certain that AIDS is not transmitted through intact skin tissue. That means that touching, stroking, holding, caressing, masturbating or kissing (anywhere except the anus, vagina or head of the penis) can be considered safe. These behaviors are safest **only** when and where the skin of both partners is intact. Forceful, deep kissing may increase risk since such pressure can cause tiny breaks in the skin inside the mouth and therefore enable blood to be exchanged. Exchange of bodily fluids could occur anywhere the skin is broken.

The use of condoms during oral, anal or vaginal sex may make these activities safer. (It is still unknown whether a virus, the likely culprit in AIDS, can penetrate rubber). Sex is also likely to be safe with the use of condoms and/or thin rubber gloves with mutual masturbation, whether the focus is on the anus, penis or vagina. (Thin, disposable rubber gloves can be found in a pharmacy.) A thin condom is probably adequate for oral sex on a man, but safe vaginal and especially anal sex require a more heavy duty condom. Plenty of lubrication (nonpetroleum based) and less aggressive thrusting should prevent breakage. The condom should be removed carefully after withdrawal using rubber gloves and discarded in a plastic bag; hands and penis should then be washed with soap and water. This process should be observed following either vaginal or anal penetration. **Always wash before and after sex.** Always use a new condom with each act or before moving from orifice to another.



Since there is some evidence that stress can contribute to suppression of the immune system, it is wise to make sex as stress-free as possible. Pain can be stressful for one's system; therefore, practices that produce pain, particularly for longer periods of time, may continue to weaken one's immune system and should be avoided. Drugs and alcohol as well can weaken or suppress the immune system. Moreover, the altered states brought on by drugs and alcohol may contribute to abandoning safe sex practices in favor of familiar but riskier pleasures.

Changes in sexual practices and explorations may be more easily accomplished within the context of an ongoing relationship. For a single person with AIDS, being sexual the first time with someone may be more problematic, but not at all impossible. The partner must be told of the condition of AIDS and of the necessary restrictions involved in sex. Fully informed partners increase the likelihood of cooperation with the above mentioned guidelines for health conscious sex and, therefore, limit the spread of the disease. AIDS is a life-threatening illness and every effort must be made to inhibit its spread.

The same considerations apply to any individual who has been sexually involved with a person with AIDS, particularly one who is or has been a regular partner of a person with AIDS. Because the length of the incubation period is unclear and an individual can carry the disease without being diagnosed, safe sex guidelines should be followed at all times, particularly among high risk groups.

Realistically, it is likely that many potential partners will not be interested when informed of the diagnosis of AIDS. But some will be. For most people with AIDS, there will need to be more discussion with possible partners about sex before than most people have been used to or comfortable with. It is unlikely that potential partners will be as aware of the guidelines of health conscious sex and will need to be informed and educated by the person with AIDS.

## **Changing Sexual Behavior And Attitudes**

Limitations are often frustrating, and reading a list of AIDS "do's and don'ts" is probably no exception. Don't let it contribute to a sense of futility. Keep in mind that the list of precautions and prohibitions is specific and finite; the "do not" list is much shorter than the list of what is safe and possible to enjoy. Focus on what you can do, be positive, and enjoy it.

Many people have rather limited views of what sex is. For example, for some it is restricted to something like arousal, insertion, and finally climax. For others sexual play may follow a different routine. As a result of AIDS some people will take the opportunity to develop additional and varied intimate interactions that are satisfying.

One can change attitudes and behaviors. Many of the specifics of how one likes to have sex or make love are **learned**; what excites an individual today may differ considerably from what was especially enjoyable in previous years. For example, many people can remember that the idea of orally stimulating a partner's genitals was at first repulsive, yet it may have become a favorite sexual activity. Perhaps, with some time and repeated experiences, it may be possible to develop such erotic associations with condoms and other practices which can have obvious health benefits.

These examples suggest that it is possible to develop new ways of enjoying sex unless pride, fear, anger or some other emotional resistances block experimentation. Adapting and experimenting will be more difficult for some because of the sexual guilt and inhibitions that most people have internalized to some degree in our society, regardless of how sexually active one has been or how creative one may have been in past sexual behavior. Some persons with AIDS will be able to make the accommodations to a terribly unfortunate and difficult situation and achieve surprising new levels of sexual satisfaction.



It is easier to make these changes if one can talk somewhat comfortably and openly about sex. This process may begin by voicing one's need for physical intimacy while acknowledging the fears regarding transmission of AIDS or the vulnerability of one's own health related to that exposure. Even though previously one may have been uncomfortable with such questions as "What do you like to do in bed?", some discussion of "What can we safely do?" or "Let's try . . .," may now be necessary in order to feel safe, avoid transmission, and be physically prepared with preventive supplies like condoms. Talking openly about the frustrations and disappointments when things do not work out the way one had hoped is often helpful. The experience of making all the necessary preparations and taking precautions with someone — sometimes awkward, inhibiting, embarrassing, frustrating, sad or funny — can increase affection between two people and, in turn, can be especially reassuring for someone who is seriously ill.

The need for physical intimacy is great; so is the concern about transmission. Aspects of previous sexual patterns will be missed, some more than others. Changing sexual patterns and habits is difficult, but for most persons with AIDS it is necessary for his/her own safety and the health of others. Because of AIDS, sex is not likely to be what it was before; but with the full knowledge and cooperation of one's partner and an openness to new experiences, satisfying sex and intimate pleasures can be achieved.

Having AIDS does not have to mean giving up sex, but it does mean some changes in attitude, approach and activity. The process of such change can contribute to the expansion of sexual pleasure, emotional growth, and the satisfaction of being able to adapt. It can lead to development of more intimate and satisfying relationships with others.

## **Risky Gay Sexual Practices**

To this point we have focused on providing general guidelines in a positive manner about safe sex. We feel that perhaps we should comment further on specific risky sexual practices.

### **Fisting**

Fisting is risky, at best, for both partners, but especially for the fister; the fistee's bodily fluids (blood, feces) may penetrate even tiny breaks in the skin of the fister's hand or arm. If fisting is very important, the use of a high glove and gentle movement reduces the risk considerably. **APLA does not recommend this practice under any circumstances.**

### **Piercing**

Piercing as a shared sexual experience increases risk not only because blood is likely involved but because it results in the increased risk of exposure to broken skin over some extended period of time. Additionally, as mentioned earlier, pain can cause stress, and prolonged stress can suppress immune system function.

### **Rimming (Scat, watersports)**

It is impossible to use any precautions to make rimming, scat or watersports safe.

## **STRESS: ITS CAUSE AND CONTROL**

**Jaak Hamilton, M.F.C.C. and Scott Sherman, Ph.D.**

When considering the issues of stress — its control and reduction, as well as its health impact — it is important to understand that there are varying levels and types of stress. The purpose of this article is to offer some suggestions about (1) how to recognize situations that cause stress, (2) recognize when you are feeling stressed, and then (3) determine **positive** actions to eliminate or minimize the impact of the stress-inducing situation.



Stress presents in different ways and in many settings. It can occur because of situations over which we have little or no control. Examples of this might include natural disasters (floods, earthquakes, etc.), traffic problems, or power failures. Such episodes often leave us feeling victimized. **Understanding** and **accepting** that we have little control of these situations is the first step; the second is learning to **cope** with them.

A second form of stress is that over which we **do** have some control. It is the stress that we often bring upon ourselves, that we may not recognize, or which makes us victims of ourselves. This is where it is helpful to take preventive steps and learn how to control or minimize stressful situations.

One approach to stress management is to know **your** early warning signs of stress. There are many ways to do this, and they may be different for every individual. In fact, levels of stress and what is stressful differ for each person. For some people stress can be a motivating factor, while for others it may inhibit or limit their ability to function. You must know how stress works for **you**, and when it rises beyond a workable level, hit your red flag and set a stress management plan into action.

Signs of stress can present physically or psychologically, and again, they may differ for individuals. The following are common.

#### **Physical Signs of Stress**

- Tension headache
- Tight neck or shoulders
- Eye strain
- Upset in usual sleep pattern
- Upset stomach, "butterflies"
- Disrupted eating patterns
- Rash
- Hyperventilation (short, rapid, shallow breaths; panting)

#### **Psychological/Emotional Signs of Stress**

Feeling:

- Tense or edgy
- Depressed or blue
- Short tempered or unusually impatient
- Disoriented, scattered
- Short concentration span

Stress management takes many forms; you will have to determine which is most appropriate or useful for **you**. Perhaps one of the most effective (and healthful) means of controlling stress is physical exercise. This does not mean a 10-mile jog or hour of wrestling. Do what you can, what your health allows. A casual stroll can be as beneficial as a light jog, or try swimming (easy on the body), bike riding, a short hike in pleasant surroundings. There are endless alternatives.

Other activities that help relieve your mind are also helpful. Watch television, or sit in a jacuzzi. (In lieu of a jacuzzi, try a hot bubble bath — don't laugh. It works beautifully, it's cheap and almost everyone has a bath tub.) Get involved in activities which are fun and enjoyable. How about cards or a game of Trivial Pursuit? Many cities have clubs which offer options like movie-going, bridge, bowling, Dynasty night. Check out your area and interests. If you do not find what you like, take some initiative. Start an activity yourself. Do not wait for someone else to take the ball; run with it.

Other methods of stress reduction might include mental or spiritual exercises such as hypnosis or meditation. Biofeedback is an excellent tool. (You can purchase a manual biofeedback machine for \$15 at Radio Shack.) Guided imagery and deep muscle relax-



ation are also very useful. You can learn to do these on your own or purchase tapes to aid you. Deep breathing, a preliminary for most relaxation exercises, is easy and you can do it anytime and anywhere.

As has been seen in gerontology studies, pets can play an enormous role in reducing stress and bringing calm into chaos. Whether it be the stroking of a dog's fur, the playfulness of a cat, the laziness of a fish, pets can be hypnotic and relaxing. **A precautionary note:** Before selecting a pet, immune suppressed individuals should check with their doctor. Some animals and their care may put people with AIDS or AIDS Related Complex at risk of developing certain infections.

Additionally, there are some structured exercises that can help prevent or control stress. You might list activities or individuals that you find particularly stressful, or make a list of activities on a timeline so that you can put events in perspective. Then see how you can restructure these to make them more workable. Plan ahead so that you can take pressure off, and pace yourself.

Above all, cultivate those people in your life who are supportive and healthy. Have more dinners with friends. Have people over to play Monopoly, cards or just a night of television.

It is imperative that we all understand that stress can undermine our health — spiritually, emotionally, mentally, and physically; we must guard against it. We must treat ourselves kindly, with care and love. We must attend to and address our needs on all levels. We are holistic entities and must not ignore one facet of our lives while taking care of another.

Surround yourself with positive influences and thoughts. Make your activities work for you, not against you. Find time to be alone, peaceful, and learn to enjoy that which is you.

## **AIDS AS A TERMINAL ILLNESS**

**Robert W. Krasnow, M.D.**

### **Death and Dying**

"Because I could not stop for death, he kindly stopped for me," wrote poet Emily Dickinson. Will death stop for you? I suspect you have wrestled with that prospect. A diagnosis of AIDS evokes the possibility, or even the probability, of your own death. This wrestling match must surely represent the greatest challenge of having AIDS or any potentially fatal illness. Struggling with death brings into focus your past, your present, and your future — all that was, all that is, and all that might have been. It is a time during which you are most likely to reassess your faith, your beliefs, values, priorities, the meaning of time, and thus, life itself.

I hope you will find what follows to be helpful and supportive as we discuss death and dying.

### **Stages of Dying**

Elisabeth Kubler-Ross, in her now classic book "On Death and Dying", describes five stages through which dying persons may go. Dr. Kubler-Ross, a psychiatrist, arrived at these stages through her in-depth work with terminally ill people. I present the stages to you now, although you may already have knowledge of them, because it is often helpful to have an intellectual understanding of what you may be experiencing.

These stages are descriptions of differing psychological states, and are not necessarily experienced in the order given. They may occur separately, simultaneously, in any order, and may appear, disappear and reappear. However, they are listed here as Dr. Kubler-Ross listed them.



**Shock and Denial.** This may occur at the first signs of illness, at diagnosis, on being told the illness is incurable or fatal, or anywhere in between. You, like others, may say or feel, directly or indirectly, "It can't be!" and "No, not me!" The shock may evoke a complete absence of feeling, or emotional numbness. This may be brief, long-lasting, or intermittent.

Denial can take many forms, and is best understood by hearing what some people say:

"All this concern, and I'm not really sick."

"AIDS? It's not AIDS. It's just a flare-up of my old hepatitis."

"AIDS! Big deal. I'll probably die in a traffic accident first."

"What do doctors know? I don't plan to change my life a bit."

"The new treatment is going to cure me . . . I'm sure."

Thus, persons with AIDS or other life-threatening illnesses may deny that they are ill at all, that their diagnosis is correct and possibly fatal. They may deny that they are troubled by the diagnosis, or that they will change their life style. They may make unrealistic plans, or refuse limitations.

Denial can come and go, and is **often helpful in coping**; it is a "bad" thing only when self-destructiveness results.

**Anger:** Your feeling may be "Why me? Why not you? Why not him?" There may be feelings of bitterness and resentment. Anger may be directed at God, or doctors, or a dozen other things. It is often helpful to ventilate anger to someone willing and able to listen.

**Bargaining:** It involves feelings like, "Yes, it is me, but . . ." But "I want to live until Christmas," or "until my birthday," or "until my family arrives." It may involve wanting to do a special thing one last time. Most bargains are struck with God, and the bargaining may signal a better ability to face the ultimate facts if they can just be put off a bit.

**Depression:** This often follows the acknowledgement that, "Yes, it is me" . . . the dealing with the harsh reality of what is happening. Again, it is important to be able to talk to someone who is receptive and sensitive about the sorrow and heartache — someone with whom you can cry comfortably.

**Acceptance:** It is at this point some people reach that marks their coming to terms with what is happening, possibly even seeing it as a welcome release. This is **not** necessarily a goal, and for many people it simply may not happen. Whether or not you reach acceptance is neither a good nor bad reflection on you.

## **Your Feelings**

What will any of us feel in this last portion of our lives? What will you feel? The answer depends largely on your present situation, what makes you a person, your life experiences, how you resolve lost hopes.

We have looked at five stages of dying, which include feelings of anger, depression, hopefulness, and calm. A wide range of human emotions may be experienced during this time. Some of these are: sadness over losses and those yet to come; anxiety about the unknown, or the known; despair, guilt, shame, outrage, hurt, and even joy. I have listed but a few of the positive emotions, as they are rarely a problem to deal with. The negative emotions, if quite intense, can be disabling and demoralizing.

Help is available when feelings become more than you can cope with, and it is important not to adopt an attitude of "How do you **expect** me to feel?", but rather, "Can I feel **better** in spite of this?" Utilizing mental health workers, such as psychiatrists, psychologists, social workers, or counselors who are aware of and sensitive to the psychological and emotional turmoil that accompanies a diagnosis of AIDS, makes sense.



## **Significant Others**

Sometimes it may seem that there is enough to do looking after yourself without having to think about others. It will help to remember that those especially close or linked with you (lover, spouse, parent, sibling, child, friend) will be undergoing their own complicated reactions to your illness, declining state, and possibility of death. They, too, may be experiencing some or all of the stages Dr. Kubler-Ross identified, with the consequent denial, anger, bargaining and depression, and their behavior may be very unpredictable. They may be helpful or negligent; present or absent; angry about the AIDS, your homosexuality, your lifestyle, or very understanding. They may stand by you, or disappear in avoidance. Their reactions may not be as absolute as I have presented, but shades of gray in between. It is likely that their feelings may encompass contradictory emotions much as your own do. You are going to have feelings about these important people's reactions and behavior that may range from hurt and angry to reassured and grateful. You are entitled to your feelings, but if you find them so troubling that they are having a negative effect on you or on a relationship that is important to you, you may wish to seek assistance with them. A relationship you value can offer needed support at this time, and it will be worth the effort to understand and resolve mutual negative feelings, rather than rejecting the relationship out of disappointment or anger.

## **Finishing Life's Business**

How devastating it can be to lose control of so many areas of your life while terminally ill. So many things you might have done. So much left unsaid and unfinished. Yet this, in large part, is what coming to terms with dying is about. And since we all die, whether suddenly or after an incapacitating illness, coming to terms with our own dying is part of each of our lives. I am saying that coming to terms with death means coming to terms with life — life that is filled with uncertainty, limitations, thwarted aspirations, and an often abiding sense of incompleteness.

What is to be done? What can you do for yourself? You can regain a sense of control by attending to "real world" concerns, such as your will or property, and by participating in decisions about your treatment. You can survey your life to find what has been most pleasant, most meaningful, most fulfilling, and most rewarding. You can avail yourself of the opportunity to bridge some gaps or mend some fences with friends, family, and other significant people. This will help with a sense of completion — of having made life's circle whole.

Last, and of special importance, is achieving some sense of inner peace and order. This will involve not only acknowledging death's inevitability, but dealing also with long-standing conflicts about yourself and your life. For example, if you are gay, it may mean further resolving your feelings about your homosexuality. It may mean dealing with feelings about your career, your relationships, your family, your faith, or the illness itself. This may require the help of a professional, but it is you who must provide the willingness and the openness to put your life and its meaning in perspective.

## **The Right to Refuse Treatment**

You have the right to refuse treatment. You may choose not to exercise this right, but it is important for you to know that the choice is yours. This is a legal right that says you have ultimate control over your own body.

In a 1914 decision, Judge Benjamin Cardozo of the New York State Supreme Court declared: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." You have the right to refuse treatment regardless of the consequences to yourself; however, if the consequences may be harmful to others, public health laws override this right.



## Hospice

"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die," wrote Dr. Cicely Saunders. Dr. Saunders founded St. Christopher's Hospice, outside London, in 1967.

During the middle ages, hospices were way stations or houses of rest for pilgrims and other weary travelers, as well as for the sick and the dying. In 1967, with the founding of St. Christopher's, the modern hospice movement was born, and today there are hundreds of hospices throughout the western world.

Hospice embodies a philosophy of caring for a person with a terminal illness in a way that promises life will end peacefully, in a comfortable, caring environment.

What about hospice for you? Currently, hospice home care programs are assisting persons with AIDS to stay at home. Few AIDS patients are utilizing inpatient hospices, primarily because the nature of opportunistic infections requires specialized medical care which is not available in hospice. People usually choose hospice care when curative measures are no longer possible or desirable.

Hospice's great value is in its resurrection of an old belief — that death is a part of life and need not be a time of abandonment of yourself, your personality, or your uniqueness. "Living until you die" is the essence of hospice, and as we have choices about how we live, each of us can have choices about how we will die. Hospice encourages tending to those areas of one's life that give it meaning. The opportunity to "tie up loose ends", to complete relationships, to reflect on what our having lived has meant to us and others, can offer a sense of harmony and peace at life's end that may have escaped us during life itself.

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## **SECTION VI**

### **GETTING YOUR HOUSE IN ORDER**

- Tapping Social Services
- Health, Disability and Life Insurance
- Taking Care of Business — Legal Resources

#### **TAPPING SOCIAL SERVICES**

**Coleen Johnson, MSW**  
**Director of Psychosocial Services**  
**AIDS Project/Los Angeles**

Many persons with AIDS are faced with the challenge of applying for social services. The experience can be smooth and gratifying or frustrating and unproductive. While some parts of applying are essentially "out of your hands", you can have a considerable effect on most of the application process. Keeping a positive, persistent attitude during the course of your applications is extremely helpful. Enlisting the help of sympathetic persons is beneficial as well. Other ways to make things run smoothly are to maintain a polite but firm attitude with agency staffs, complete paperwork conscientiously, and prepare your application so as to reflect a convincing picture of someone who needs aid. If after all your diligent efforts, you do not receive what you believe you are entitled to, there are ways to address your grievances effectively.

Most persons with AIDS learn of their diagnosis in the hospital, while many learn of it as an out-patient. Often one's first reaction is disbelief. Other feelings may include despair, anger, and sadness. It is difficult to begin work toward any goals when your feelings are so fresh and confusing. Take some time to allow yourself to process what is happening before you make any major decisions such as whether to apply for social services.

One very important piece of information that you will need to obtain from your physician is whether or not you have AIDS according to the Center for Disease Control (CDC) definition. Occasionally, a physician may be reluctant to give out this information. Be insistent that he or she provide you with this as soon as possible so that you can begin to make decisions about your future. Your physician will need to make certain tests to establish a diagnosis of AIDS, but should inform you of the results soon after he or she knows them. This is important because if one has CDC defined AIDS, it is much easier to establish eligibility for social services.

Another important point to consider is whether the decisive factor in your diagnosis is a positive biopsy for Kaposi's Sarcoma (KS) or an opportunistic infection such as bronchoscopy-proven case of *Pneumocystis carinii* pneumonia (PCP). Some individuals have both the opportunistic cancer and opportunistic infections. There is some indication that those individuals who contract only KS may be the most able to continue in their jobs. It is important to discuss with your physician what he or she expects regarding the course of your illness. Ask him or her to be as realistic and honest as possible, and explain that you will be making important decisions based on the information he or she gives you. You might want to take the physician's personal style into account here: has he or she always downplayed the seriousness of your physical condition, or has he or she been gravely concerned about every lab test? This may give you an idea of how to interpret what your physician tells you about returning to work.



If you are in the hospital and are having difficulty coming to a decision about returning to work or dealing with your feelings about your diagnosis, you can request a psychiatric consultation or visit with a hospital social worker. In certain large metropolitan areas there are local AIDS-related organizations that can send someone to visit with you and discuss these matters. The advantage of doing this while you are still in the hospital is that the social worker can help you with the applications processes. Ideally, the social worker should come to visit and assess your needs without your asking, but in reality you may have to ask for one. Be insistent that a social worker comes to see you if there should be a delay of more than one day. Remember, after you are discharged you will no longer have access to this helpful person.

The social worker or psychiatric consultant should be able to help you talk about your feelings about applying for public assistance. You may feel too proud to apply, thinking that you've always paid your way so far, so why stop now? Or the word "disability" may be offensive to you, bringing up feelings of helplessness. These feelings may cause you to delay your applications, which can be problematic three months down the line if your savings give out and you aren't well enough to return to work. One good reason **not** to apply is that you are definitely returning to work with your physician's support or have a private disability plan. In any event, as always, it is better to be safe than sorry. One runs far less risk by applying early and having to cancel applications than by not applying and finding that one is unable to return to work.

In the long run, the decision about returning to work or applying for social services is yours. Some persons with AIDS feel more comfortable continuing with their regular schedule, in order not to think about their illness all the time. Others prefer to remove any source of stress from their lives and rest as much as possible.

Applying for social services can be trying. One of the best things you can do is enlist the help of others. Besides the hospital social worker or representative from a local AIDS-related agency, you may want to ask a friend to help you through the process. Choose someone who is confident and whom you trust. Ask them to accompany you to various agencies or to intervene on your behalf when you are too ill or frustrated to do so. Do everything you can on your own. It will help you to feel more independent, and then your friends will be happy to help when you really need them.

Another important thing to do is to begin a notebook. Note all pertinent information concerning your application. Entries might look like this:

|          |                                        |
|----------|----------------------------------------|
| Date:    | September 24, 1984                     |
| Time:    | 1:30 P.M.                              |
| Contact: | Coleen Johnson, MSW<br>AIDS Project/LA |
| Phone:   | (213) 871-1284                         |

Subjects  
Discussed:

Ms. Johnson recommended that I apply for both California State Disability Insurance (SDI), Federal Disability (SSD) and Supplemental Security Income (SSI). I applied for these upon leaving the hospital. Set up an appointment with her to discuss this in detail September 28, 1984 at 3 p.m., AIDS Project offices, 937 N. Cole, Suite 3.

|          |                    |
|----------|--------------------|
| Date:    | September 28, 1984 |
| Time:    | 3:00 P.M.          |
| Contact: | Coleen Johnson     |
| Phone:   | (213) 871-1284     |

Subjects  
Discussed:

Ms. Johnson suggested that I apply for Medi-cal in addition to what I have already done. Gave me address and contact person, Mr. Jones at 821-1234.



Date: October 3, 1984  
Time: 8:30 P.M.  
Contact: Ms. Smith, Eligibility Worker  
Department of Social Services  
(Mr. Jones was out sick)  
Phone: (213) 821-1234

Subjects  
Discussed:

Ms. Smith stated I was ineligible for Medi-cal. (?)

Date: October 3, 1984  
Time: 1:30 P.M.  
Contact: Coleen Johnson, MSW  
AIDS Project/LA  
Phone: (213) 871-1284  
Subjects  
Discussed:

Date: October 3, 1984  
Time: 9:00 A.M.  
Contact: Coleen Johnson  
Phone: (213) 871-1284

Subjects  
Discussed:

Am I ineligible for Medi-cal? Coleen says no. She'll call Ms. Smith and her supervisor.

Date: October 4, 1984  
Time: 9:00 A.M.  
Contact: Coleen Johnson  
Phone: (213) 871-1284

Subjects  
Discussed:

Coleen says she yelled at Ms. Smith and her supervisor, Ms. McDonald (321-1237). I should go back tomorrow at 8. Don't be discouraged. Call her if any other problems.

Date: September 24, 2984  
Time: 1:30 P.M.  
Contact: Coleen Johnson, MSW  
AIDS Project/LA  
Phone: (213) 871-1284

Subjects  
Discussed:

Ms. Smith very apologetic and helpful. Completed paperwork, should hear within three months.

If you do this, it will save you a lot of trouble. It will also enable you to follow up on people who gave you false information, were rude, or "AIDS phobic."

Do not hesitate to ask in a polite manner for the name of someone's supervisor if there is a problem. Advise the supervisor of the problem and ask for their help. Usually having an agency helping you (such as a local "AIDS Project") will get much quicker results. Do not be afraid to use the names of personal political contact or other powerful persons. If you do not know someone like this, call and enlist the support of persons you think might be helpful to you, such as gay politicians.

When filling out applications, do not attempt to complete all the paperwork in one day. This can be frequently mentally and physically fatiguing. Instead, set aside several periods when you can work on this over a week or two. An important point to remember is that public assistance is for people who are poor and disabled. If you are independently wealthy and actually able to work as well as you once were, the government is not going to be interested in giving you money. If you have stocks and savings accounts, you are



expected to use most of these assets for your expenses before applying for financial aid. There is some examination of your finances retroactive to your application, so do not attempt to hide your assets by putting them in your lover or mother's name the day before you apply.

It is important to include **all** details in reference to your physical status. Include all symptoms (memory loss, lack of energy, weight loss, chronic diarrhea, poor concentration, etc.) with pertinent dates, physicians seen, and hospitalizations. In order to be eligible for most assistance, you must be considered "permanently disabled" for a projective period of one year. This means that you are completely unable to work in **any** type of function. So you must convince the funding agency of this with the help of your physician(s).

There are exceptions to every rule. Programs differ from state to state. Some may allow shorter periods of disability or larger bank accounts. If you are not hospitalized and need assistance through the application process a psychiatric social worker at your local community mental health center may be able to help you to sort out the different programs available to you, and your feelings as well.

One thing that is fairly consistent from state to state are the social security programs. One is Social Security Disability (SSD). This pays a certain amount per month, provided you have paid into it (i.e., withheld from payroll checks), for disabled persons. Another program, Supplemental Security Income (SSI), brings your income up to a base level either with SSD or separate from it. The Social Security office closest to you can be found by looking in the phone book under U.S. Government. Other pertinent agencies can be located in the same manner under State and Local Government listings. Leaf through these pages of your phone book to familiarize yourself with any potentially helpful programs. Some cities have information and referral services which may help you find less obvious programs to assist you.

If you do not get results from your application which you believe are fair, inquire about the redress of grievances. Follow through on the process with the same methods you used for your initial applications. Remember to keep a positive persistent attitude, use others for support, and be assertive. Also remember that many other persons with AIDS have done what you are attempting and have succeeded. Good luck.

## **HEALTH, DISABILITY AND LIFE INSURANCE**

**Brent Nance, CLU**

This guide is primarily written for persons with AIDS who have concerns about their insurance policies, including health, life and disability. Even under the best of circumstances reading and understanding your insurance policies is a bit like learning a foreign language. However, with this guide (and a little patience and effort) you will have a greater comprehension of your coverages, know what they will do for you, and what to expect. This understanding will help to maximize use of your benefits and make the handling of your paper work easier. It should also help reduce your stress level by knowing the what, when, and how of your coverages.

Think of this exercise not as a chore or a pain in the neck, but rather as a challenging growth experience. You could also think of it as your chance to get even with your insurance company. If nothing else, this guide might be useful when you need help falling asleep.

If you do not have a copy of your health plan, contact your employer for one. If you're covered under an individual plan, contact your insurance carrier for a duplicate copy.

I cannot over emphasize the importance of keeping good records of your insurance



papers, claims and all communications with your insurance company. Don't throw out anything. You should keep a separate file for each type of policy you may have (health, disability, life). You may find it necessary to refer to the letters, bills and claims information from time to time. Each time you talk to anyone regarding your policies you should jot down with whom you spoke, what was said, the date and time. You might have to remind someone of what was said. It might be useful to start an insurance diary to do this. It is so easy to forget whom you spoke to and what was said after dealing with your insurance questions over a period of time. Always have your insurance policy number, social security number and all certificate numbers handy when you call your insurance company. Always use these numbers whenever you write to your company. They must be able to identify who you are and what policy you are writing about. Some companies will issue you a claims number when you file for benefits. You will have to give this number to them anytime you inquire about your claims. See appendix #1 in this section for a sample form you can use to record important information about your policy. This form can be copied and handed out to your doctors, hospital or others who may need it.

This guide is broken down into three major sections: 1) HEALTH INSURANCE, 2) DISABILITY INSURANCE and 3) LIFE INSURANCE. Both group and individual coverages are discussed.

If you have recently (in the last 31 days) left employment where you were covered by group insurance you need to contact your former employer and get the necessary information on your conversion rights under the policy. The conversion rights in your group policy allows you to apply for an individual policy without answering health questions. This may be your last chance to get or keep your health insurance. See the conversion section under health insurance and the same section in your policy.

**Remember** that there are means available to help you understand your benefits. Your employer's personnel office, the insurance company claims office, insurance counseling through your local AIDS Project, and/or your own insurance agent/broker should all be able to help you with any problems or questions you might have. Remember, it is the **duty** of the insurance company to inform you of your benefits. They work for you, so don't be shy about asking for details.

## **HEALTH INSURANCE**

In order to understand your health insurance benefits you need to have a working knowledge of the major terms explained in your policy. Once you understand the terminology you will be able to read and fully understand the outline of benefits (usually given near the beginning of your plan book). In the appendix you will find a summary form you can fill out. It will help summarize all of the major areas of your coverage on one page and will enable you to review your coverage easily.

### **Maximum Benefits:**

The maximum amount or level of payment your policy provides is usually stated as a lifetime maximum benefit per person. Limits of \$500,000, \$1,000,000 or even "unlimited benefits" are customary. Obviously, the larger the maximum, the higher the benefits that can be paid out in claims. Some policies have a "per cause" maximum. "Per cause" means a new maximum will be determined for each individual unrelated illness or accident.

### **Usual, Customary and Reasonable:**

Most medical plans pay benefits according to a usual, customary and reasonable scale. A "usual" fee is the price usually charged by a physician for a given service. A fee is "customary" when it is within a range of charges made by other similar physicians in your area. A fee is "reasonable" when it is within the above ranges and is justifiable



based upon the need for the treatment of your condition. If a doctor charges more than this, the balance will not be paid by the insurance company. Of course, some companies' usual and reasonable fee limits are more reasonable than others. Don't be afraid to ask your physician for the technical name of the procedure. You can then call your insurance company claims office and see if the doctor's fee is within their limits. If not, you might negotiate a lower fee with your doctor.

If your insurance company cuts back its benefits (pays less than the full 80% or 100% you expect), you can appeal your claim to the company (see the claims section below). If they will not approve the fee and you feel that your doctor's fee is about the same as that being charged by other doctors in your area for the same services, then you might appeal to the State Department of Insurance. See "claims".

### **Deductible:**

Almost all plans provide for a "deductible", an amount you must pay before the insurance company will pay any benefits. Your deductible may be \$100, \$250, or even larger. You usually must meet a new deductible each **calendar** year before benefits can be paid. Often there is a three month, year-end carryover. If, for example, you have not reached the deductible by October 1, any medical expenses incurred during October, November, and December can be used to meet the next year's deductible.

A "per cause" deductible is provided by some plans. In such plans, a separate deductible for each illness or accident must be paid. A per cause deductible may not have to be accumulated during a calendar year, but usually must be accumulated during a specified time period.

### **Co-Insurance:**

The co-insurance clause tells you what **percentage** of your bills the insurance company will pay and the percentage of the bills you must pay. Usually the insurance company will pay 80% of all claims (after the deductible). You will pay the remaining 20%. In many plans the 20% you must pay stops when claims reach a certain level. This is known as the "stop-loss" point.

### **Stop-loss:**

Comprehensive insurance plans will usually pay 100% of the cost for medical care after you have been paid a certain level of benefits. This "stop-loss" provision usually starts after expenses reach \$2,500 or \$5,000 during the year. Once your claims reach this point the insurance company will pay 100% of all additional bills that would have been paid at the 80% level before. The next calendar year you may have to start over again.

### **Hospital Room and Board/Intensive Care:**

Some plans pay only a specified room rate per day, even if the hospital charges more. If so, your plan will state a set dollar amount which they will pay per day for semi-private room and/or 3 times the average daily rate for intensive care. Other plans will pay the usual and customary hospital room rate for semi-private and the usual and customary rate for intensive care charges.

Many persons with AIDS who need to be hospitalized are placed into what is called an isolation room. This is to protect you from exposure to the various infections that abound in hospitals. There is an extra charge for this special service. Some plans will pay this extra charge without comment, others will not cover it at all, while others will need to have special documentation from the doctors and hospital that there was a "medical need" for such a room. It is important that any person with AIDS for whom this service is not paid ask the insurance company to review the claim for payments. Just call the claims department and explain that you required an isolation room because of your medical condi-



tion and ask them to review your claim. They may write to your doctor and hospital to verify the medical need for the room. You can always appeal your claim to the proper state body (see CLAIMS section).

### **Surgery: Scheduled/Non-scheduled.**

Most plans will pay for any surgery claim that fits into their usual, customary and reasonable limits (see above). However, some plans will pay only a pre-set amount for any surgery regardless of what the doctor charges. If your plan pays at the usual and customary rate and still does not fully cover an item at the proper level, you can then appeal their decision to their claims examiner. Often with additional support information from your doctor or surgeon, they will pay the balance due. If not, see if your doctor will lower his/her charge to the level acceptable by the insurance company.

### **Psychiatric Coverages:**

Read this section of your coverage carefully. Many persons with AIDS utilize these benefits. Most plans offer good coverage for psychiatric care while hospitalized, but offer only limited coverage for treatment while not hospitalized.

It is common for plans to pay only 50% of the usual and customary rate for psychological treatment out of the hospital. There may be an additional limitation of \$10, \$20, or \$25, maximum payment per visit and a limit of one visit per week.

Check with your local AIDS organizations. They may offer individual and/or group counseling at little or no cost.

### **Exclusions and Limitations:**

All policies have exclusions (things not covered) and limitations (things only partially covered) automatically written into them. Most exclusions have been standardized by the insurance industry. It is important that you read the excluded list of services carefully to become familiar with items and care not covered under your plan.

### **Pre-existing Conditions:**

An illness or condition which existed and was treated or which should have been treated before coverage started is a pre-existing condition. The wording varies with each plan, so read this section carefully. If a condition falls into this provision, it may not be covered until coverage has been in force for a certain period of time. If you have had your coverage for over two years then you generally will not have any problems with claims under this portion of your policy. If you have your claims denied under this clause, you might have a valid appeal. Read this section in your policy; and if you still believe that they should have paid your claims, then you can appeal. (See claims section.)

### **Home Health Care Expense Coverage:**

Today companies often include this benefit in their plans. It allows payment for care provided by an "authorized home health care agency" that starts within a specified number of days after a hospital confinement. This at-home care is usually limited to a maximum number of visits or days (100 to 120) per year.

Home health care services include some or all of the following: part-time nursing care, home health aide services, physical therapy, medical supplies, drugs and medications prescribed by a doctor and laboratory services. Read this provision carefully. If you and your physician agree to use such a service, contact your claims department to obtain detailed information and authorization.

### **Extended Benefits:**

If you are totally disabled because of your medical condition and lose your group plan



coverage (due to termination from work), you may have your coverage extended for a limited period of time (usually between 90 days and one year). **Remember that this benefit usually covers only expenses directly related to the cause of disability.** New medical conditions will not be covered. If you are put on disability by your physician, it is important that the cause of disability is defined very specifically, yet broadly enough to cover future problems that may develop due to a suppressed immune system. You may need to apply for a conversion policy at this time (see below).

### **Termination of Benefits:**

Group insurance benefits may terminate for a variety of reasons. Your employer may terminate your employment, the group plan may be terminated, the required contributions may not be made, and the insurance carrier may terminate or non-renew the coverage for the whole company. You may need to review this section of your contract and contact your employer if you have any questions relating to how long your coverage might be continued. Many times special arrangements can be made with your employer to continue coverage for a few months. Remember that the group plan will provide more benefits than a conversion policy will.

### **Conversion Privilege:**

Group health policies provide for a conversion privilege. A conversion policy is an individual policy that does not require you to be in good health to get it. It must be offered and given to you as long as you apply for conversion and pay the necessary premium within 31 days of the date your group coverage was terminated. Ask your employer if they have the necessary forms. If not, call your insurance company for them.

All states have determined what the minimum benefits are that can be offered. However, companies may provide more coverage. The California Insurance Code (sections 12670-12691) calls for specific minimums for any converted group medical coverage. These are summarized:

1. A minimum of \$100,000 in lifetime maximum benefits.
2. Co-insurance coverage of at least 75% for most medical expenses.
3. A deductible of either \$200, \$500, or \$1,000 will be offered.
4. Room and Board coverage of at least \$150 per day for semi-private coverage and 2½ times for intensive care will be offered.
5. No pre-existing conditions clause will apply to any conditions covered by the group policy.

### **Claims:**

The paperwork necessary in tracking your claims can be a real chore. In this section I hope to reduce this concern to a manageable level. Included in the appendix is a flow chart to help track your expenses and insurance payments in an orderly fashion.

It is important to learn how to fill out a claim form properly. By now you have probably already done this. It's also important to **keep a copy** of all claims submitted to your carrier for later reference. **Save everything** received from hospitals, doctors, labs, insurance companies, etc. Bookkeeping can get complicated when some expenses are billed directly to the insurance company and others to you. Only by **careful record keeping** can you keep it straight. In addition, having a copy of your claims will help in dealing with the claims department when you have a specific question or complaint.

Learn to **deal with the same person** in the claims department whenever possible. This helps build a rapport and a bond of understanding between you and the claims person. Every time you have any contact with a claims person you need to **write down the person's name, the date, and what was said.** Once the claims department gets to know that you keep accurate records you will have far fewer problems in getting them to listen to



your concerns.

Hopefully you will have no major problems with your claims being paid in a timely and accurate manner. Remember, there **are** places and people to turn to if you have problems you cannot resolve. One would be your agent or your group's insurance agent. He or she is paid to help you with any major problems you might have. All insurance companies have a medical review board where complaints can be filed if you feel you have been treated unfairly. In addition to the above methods, you can file a formal complaint with the proper State body. In California this is generally either the State Insurance Commissioner or the Department of Corporations. Which body you would file with depends on who regulates your carrier.

## **Conclusion To The Health Insurance Section**

If you are not able to handle your insurance coverage and their related problems, you might have a close friend who is good with figures help you with this task. In the case that you might be hospitalized, it would be a good idea to have someone either bring your mail to you or go through it for you so that all important matters can be taken care of promptly and you do not lose any coverage by accident.

## **DISABILITY INSURANCE**

Understanding your disability benefits can be difficult, to say the least. Trying to explain disability policies is even more difficult. First, you need to have a basic understanding of the terminology used in disability policies. Here-in lies the difficulty. There is less standardization in this market than in most other areas of insurance. I would recommend that you read your coverage(s) very carefully before reading this section. In that way you will be able to pick out the areas of this guide that apply to your coverage. Both group and individual coverages will be explained.

### **Group Versus Individual Disability Coverages**

There are major differences that need to be addressed between group disability policies and non-group policies. The "general terminology" section will pinpoint areas where the types of coverages differ, however a few words are needed here. Group policies may offer either short-term or long-term benefits or both. Short-term coverages offer monthly income benefits for a year or less, while long-term plans may pay monthly benefits for 2 years, 5 years or longer.

Group plans may or may not integrate (see "coordination" section) with public plans (state disability, worker compensation or Social Security). Some group plans will even reduce their benefits if you qualify for benefits under an individual policy. Individual policies usually do not integrate with public or group plans, however there has been a recent trend in this direction.

Several states (California, Hawaii, New Jersey, New York and Rhode Island) have mandatory public disability programs (often called State Disability Insurance). In these states many group plans offer benefits which start only after state benefits are fully utilized (usually 26 weeks). You may be eligible for group benefits if your disability continues after your state benefits have been exhausted. Check with your employer.

Group and individual disability policies differ in other areas as well. Group plans may pay benefits weekly while individual plans pay benefits monthly. Group policies may have a more stringent definition of disability (see "definition of disability") than individual policies.

Unlike group health policies, group disability policies may not offer conversion privileges. Without a conversion clause, and in the event that you lose your job (for



whatever reason) while you are able and willing to work, you may not qualify for disability benefits. In many group plans if you are disabled when your coverage terminates (because of employment termination), you may still qualify for benefits since your claim to the benefits started while you were covered under the plan. This is generally so even if you have not met the full waiting period under the plan.

Since there is often a fine-line between being disabled and not being disabled, the question of when to file for group disability benefits may be more critical than for individual policies. Discuss the possibility of filing for disability with your physician. If it looks like your job may be in jeopardy, you might look into the possibility of filing for any short and long term disability benefits you may have.

Remember, filing for disability will **affect both your group health and life benefits**. You will need to review the sections on health and life insurance, then weigh the pros and cons before filing a disability claim.

## **General Terminology**

### **Definition of Disability**

The definition of disability in your policy determines if you qualify for benefits. There are three general definitions of disability used in most policies. It is not unusual for a policy to use one definition for two or five years and then switch to a more stringent one. In addition, some policies will not pay monthly benefits if you are employed in any other job even if it is a totally different occupation than the one you were in previously. It is, therefore, important for you to read and understand your coverage(s).

1. **"Own occupation."** A sample clause might read . . . "you will be considered totally disabled if you are unable to perform the main duties of your regular occupation." This clause or one very similar to it usually applies for a given period of time (1, 2, or 5 years, even lifetime). After this period is elapsed, the definition of disability may change to a more strict one.

2. **"Any gainful occupation."** A sample clause may read something like . . . "you will be considered disabled if you are unable to engage in any occupation for which you are reasonably suited by education, training and experience . . ." It is more difficult to qualify for this latter definition than the former one.

3. **"Loss of earnings."** A sample clause might read . . . "if you suffer a loss of income because of a sickness or injury you will receive a benefit based upon the percentage of income you have lost . . ." There is usually a minimum income loss required of 20 to 30 percent. Often any income loss of 75 or 80 percent will be considered a total disability within the maximum benefit paid. Some policies will even pay a minimum benefit of 50 percent during the first 6 months of a residual or partial disability.

### **Residual Disability/Partial Disability:**

Residual benefits and partial disability benefits are similar. Residual clauses allow you to collect a portion of your benefit based upon how much your disability has lowered your income. For example, if you are earning only 60 percent of what you were before your disability, then you will be able to collect a 40 percent disability benefit. The benefit will be determined by a ratio of prior income to current income. Your policy includes an explanation of how prior income will be determined. It may be the prior twelve months or a combination of the prior two years, etc.

If your policy contains a partial disability benefit and you are not working full time, you will generally receive 50 percent of the monthly benefit for up to six months. Often before you are able to qualify for benefits under a partial disability, you must be totally disabled.

### **Elimination or Qualification Period:**

To qualify for the income benefits in a disability policy, you must meet a "waiting" or "elimination" period. A waiting or elimination period is the period of time you must be



disabled before you are eligible for benefits, i.e. if your policy has a 30 day waiting period you must be disabled for 30 days before you become eligible for any benefits. You will not receive any income for the waiting period. It is much like a deductible under auto insurance. Waiting or elimination periods generally are either 30, 60, or 90 days but may be up to one year.

In many plans you have to be totally disabled before receiving benefits. However, if your plan has **residual** benefits, you might qualify for benefits even if you have not first been totally disabled.

Once you have met the waiting period for benefits, you become eligible for monthly benefits as described in your policy. However, you might not receive your first check immediately. The insurance company must receive your claim documentation, review the information and verify it with your physicians. It helps to file early (before the waiting period ends). This gives the company time to review your claim and approve your benefits so your checks will start on time. Remember, your benefits are paid at the end of each income period (just like you were employed.)

### **Monthly Benefits/Income:**

In an individual disability policy your monthly benefit or income will be given as a maximum amount you can collect if totally disabled. You might receive a lesser amount if you qualify only for a residual/partial benefit.

Under a group disability policy your income might be stated in set dollar amounts or under a formula described in your policy. Since there are so many methods of determining the monthly benefit under group plans you will have to read your policy carefully. If you are still unable to determine the amount of income, call your employer or insurance company claims office. This information is not a secret. Do not be shy in asking questions.

Now that you have determined what your maximum monthly benefit might be, you need to know how much money you can actually receive. Your monthly income may be affected by two things: one is the coordination clause (see "coordination of benefits"), and the other is taxes. Individual benefits are usually not taxable while group disability benefits usually are. The general rules are: if you paid for the coverage with after-tax income, then the monthly benefits will not be taxed. If the premiums for the coverage were deducted from taxable income (either by you or your employer), then the income will be at least partially taxable. The tax laws regarding disability income have recently been changed. Consult with your insurance company to determine if your benefits will be taxed. If you receive benefits under your group plan the insurance company will generally withhold taxes from your checks just like your employer did.

### **Coordination or Integration of Benefits:**

Most group disability contracts and many individual policies contain integration or coordination of benefits clauses. The benefits may be integrated with either State or Federal benefits (State Disability, Worker Compensation, Social Security), and sometimes with private individual policies. An example will help you to understand how this might work.

For example, if you are eligible for a monthly benefit of \$1,500, but it is integrated with State Disability of \$600 a month, you would receive \$600 from the State plan and \$900 from your coverage (total \$1,500). The two together will provide the stated monthly benefits. If the state plan runs out while your personal coverage is still paying benefits, then your plan will increase its benefits up to the \$1,500 level. If Social Security later starts paying \$700 a month then your income from the disability income plan will be reduced to \$800.



## **Benefit Periods:**

The benefit period stated in your policy will answer the question of "how long can I expect my checks to continue?" Your monthly benefits will continue until you are able to go back to work, you no longer meet the definition of disability, or you have received benefits for the full benefit period that your coverage allows. The benefit period generally found in policies varies from several months to several years. It may even continue to age 65 or longer. As discussed above, your plan may change the way in which your disability is defined. This could affect your ability to collect benefits.

Monthly benefits usually terminate upon death. However, some plans will pay a limited death benefit to your beneficiary or your estate. Read the policy fully.

## **Waiver of Premium:**

Most individual disability policies include a premium disability waiver. This clause is triggered generally after 90 or 180 days of disability. Once triggered, you will not have to pay any more premiums on the policy for as long as you are disabled. Some policies will even refund any premiums you paid during the first 90 or 180 days of your disability.

## **Pre-existing Conditions:**

You will have to read this section of your policy carefully. The wording varies a great deal between different plans. In most individual policies any medical history you listed on your application and accepted by the insurance company will not be used to deny benefits due to a pre-existing condition. In other cases there is a two year pre-existing condition clause. If you are denied benefits under this clause, you will need to review your policy carefully. If after reviewing your policy and the copy of your application (inside the policy) you feel it was not properly applied, you can appeal the decision (see "potential problems").

## **Exclusions:**

Most policies have only a few standard exclusions, such as: war, pregnancy, self-inflicted injury, pre-existing conditions and attempted suicide. Your policy may also have been issued with a **special exclusion rider**, excluding a medical or physical condition that existed before you applied for the policy. The exclusion can only be applied to the specific condition listed in the policy. If you think the insurance company has unfairly denied you benefits under any part of your coverage, you need to appeal the decision to your company and/or to your State Department of Insurance (see potential problems).

## **Recurrent Disability:**

If you are again disabled by the same or related causes within six months most policies will consider your disability as one continuous disability. If this happens, the elimination or waiting periods are generally waived (you will not have to wait again for the benefits to resume).

## **Rehabilitation:**

Many plans pay expenses necessary to provide occupational rehabilitation training when the insurance company feels you could benefit from retraining in order to work in a new field. The company must approve any rehabilitation program. They will not do so if it is felt you would not benefit from it. If you have a program approved for you, they will continue to pay you a monthly benefit as long as you are in the training program.

## **Grace Period:**

All individual plans have a 31 day grace period after the premium due date, in which you can still pay your premiums. Many companies allow a few extra days to pay your



premium beyond this date. Remember, your disability coverage may be one of your most important assets. An effort should be made to hang on to it.

If you are disabled and the insurance company has not yet waived the premiums, make all efforts to pay the premiums when due. If you need to, see if you can borrow the money from family, friends or one of the AIDS groups. Usually this money will be returned to you under the disability premium waiver clause so you can repay any loans.

## **Premiums:**

The insurance company cannot increase your premiums (dues) on an individual policy because they find out you have AIDS (or any other illness). Most contracts either do not allow for an increase in premiums or they can only increase premiums for all persons covered in your state at the same time.

## **Claims:**

To file a disability claim or an individual policy you must write or call your agent or the insurance companies service office. Ask them to send you the proper forms for filing a disability claim. Read and complete the forms very carefully. Any information that is incorrect or omitted can delay the processing of your claim. Be sure to photocopy all your forms before mailing them back to the company, and ask your doctors to do the same. Paper work has a way of getting "lost in the mail".

The insurance company will review your claim and decide if they need additional information before approving or denying your claim. They may want to contact your physician(s) for more information, or you may even receive a call or visit asking for more information. The insurance company might ask that you see a doctor of their choice to review your claim. If this happens, be sure to take with you a report from your own physician regarding the nature of your illness and disability.

It is very important that you keep accurate records of when, where and to whom you sent forms. You should write down the date, to whom you spoke, and what was said whenever you communicate with your insurance company.

Some companies are good at keeping you informed; others are not. You should not let more than 10 or 15 working days elapse before following up with the insurance company. When forms have gone to your physician(s), you need to follow up with their office to make sure they complete and mail any necessary papers to the insurance company as soon as possible. You would be amazed at how long paper work can sit on someone's desk without being processed.

Once you have received your first check, find out the time frame for which your claim has been approved. If the doctor tells the insurance company that you will be able to return to work in three or four months, the insurance company might assume you will then return to work. This, of course, would stop your disability payments. New forms would have to be filed causing a lot of trouble that otherwise might have been avoided. If the insurance company believes you might return to work in several months, you must remind your doctor to inform them if you are going to be on disability longer than first expected.

Filing for group disability benefits can be done in the same manner. However, instead of contacting your agent or the insurance company you first contact your employer for the necessary forms. Once completed, the paperwork might go directly to the insurance company or be returned to your employer.

If the benefits from your State Disability end before your group disability is in effect, you need to start the application process for your group disability about 2 months early. It takes time for the paper work to be processed and approved. By starting early, you can avoid a possible lapse in benefits.

Since AIDS is a relatively new syndrome, some problems might arise with the insurance



company accepting it as a valid cause of disability. In fact, your doctor may not even list AIDS as the diagnosis. Most companies will approve benefits based upon AIDS as the diagnosis. It might be better to have your doctor list **all** of your current related medical problems on your claim forms, including AIDS as the underlying condition. You do not want to refile for benefits because your pneumonia cleared up and you were taken off of disability when there is still the underlying problem of a depressed immune system.

### **Other Benefit Riders:**

Some policies provide a cost of living clause. If you have such a feature in your policy, your monthly benefits will generally increase at the end of the first year of benefits and often for the next nine years. The amount of the increase will be by a set percentage rate stated in your policy or by a formula tied to a national index. If after reading this section you are not sure how your benefits will change, then contact your insurance company for more information.

There may be additional benefits listed in your policy. It is not possible to explain any but the important of these in this guide. Read over any sections not discussed here, and contact your company for more information if necessary.

### **Potential Problems:**

Once in a while an individual is denied benefits entitled to him or her, faces unreasonable delays, or deals with a claims examiner that refuses to treat him or her with the respect deserved. What can you do if this happens to you? First write to the manager or vice president in charge of the disability claims department (an address can be found in your policy). List your complaints, giving all the necessary back up information you kept (time and day of your calls, to whom you spoke, what was said, copies of letters, etc.). Most companies want to resolve your problem, if they can do so, within the legal constraints of the policy/contract. If you feel that they are not living up to the contract, then you have several choices. You can file a formal complaint in writing with the State Department of Insurance. You might also consult a lawyer for advice. Insurance companies have been known to respond very well to threats of legal action when it appears on a lawyer's letterhead.

Seek help from your agent or the office where the policy was purchased. Sometimes a call to the insurance company from someone who can understand the jargon will help get the checks rolling. If not, the agent might be able to help explain where the paper work is and what needs to be done to push it through the system. Local AIDS organizations may also offer insurance counseling services.

### **Hospital Indemnity Policies**

Hospital Indemnity policies (they may be group or non-group) will pay a set amount of income for each day you are hospitalized. The amount will usually be between \$20 and \$100 dollars a day. The benefit will be spelled out in the policy. You can generally have the checks sent either to you or to the hospital. If you already have one of these plans, look it over carefully to see what benefits it may provide, when hospital benefits would start and what exclusions might apply. Some of the same clauses that appear in disability policies can be found in this type of policy. You should not have any problem understanding the policy.

### **LIFE INSURANCE**

Generally, everyone should review his or her life insurance policies every few years or when any major change occurs in one's health, financial status, or relationships. Now is as good a time as any.



A quick review of basic life insurance terminology may be beneficial at this point. Basically, life insurance is a contract between the insurance company and the insured/owner to pay a death benefit to the named beneficiary upon proof of death. Coverage may be provided by an individual or group policy of both. The general terminology discussed below applies to both types of coverage. Differences will be noted. Remember, any time you communicate with your insurance company or agent you must identify your policy with the policy number.

## **Kinds of Life Insurance**

Generally, life insurance can be grouped into three basic categories:

1. **Whole life/endowment policies** — generally provides level death benefits, has yearly increasing cash values and premiums that remain the same. If the policy is a participating policy, it may pay annual dividends.
2. **Term insurance** — provides protection for a specific length of time (1, 5, 10 years or to age 65). It may be renewable, at the end of each term, with higher premiums charged on each renewal. The death benefit may be level or decreasing (mortgage insurance is usually a decreasing term policy). This type of coverage does not have cash values but may pay dividends. Group life insurance almost always is term insurance provided within a group contract.
3. **Universal life/interest effective life** — is the generic name for a flexible life product consisting of an accumulation account, term insurance and expense charges. The balance of the premium, after term insurance and expenses are taken out, earns interest at a declared rate of return. These indexed interest products offer variable premiums, cash values, and flexible death benefits.

The previous section will not make you an expert on the various types of policies, and you may still be a bit confused; whole books are written on this subject. However, this section helps you to identify which basic type of coverage you have.

## **Understanding Your Life Insurance**

This section will discuss individual life policies in general. A later section will discuss specific areas of group insurance. However, many of the following sections will be useful in helping you understand your group life coverages.

I will take you through your life policy, hopefully increasing your understanding of it. Having your policy in front of you will be helpful. If you cannot find your policy, obtain a duplicate from your company.

On the front or back of your policy you generally find the company's name, the address, the basic type of coverage (whole life, term, etc.), and whether the policy pays dividends. Inside the front cover should be an index to the various sections of the policy. The next page is usually the detail page. This page names the insured, the owner, the amount of coverage, the register date (when coverage started), and the policy number. The beneficiary, a table of premiums, and a cash value table (if any) may also be noted here. The beneficiary may be stated on the application attached to the policy if it is not noted here. The following is a discussion of the basic provisions and how they may benefit you. You can follow in your own policy by finding the specific sections in your index.

### **Owner:**

Generally, the insured is the owner of the policy, but it can be anyone. The owner of the policy is the person(s) who has all legal rights to the policy and controls it. An owner can determine how the premiums are paid, who the beneficiary is, and can exercise all options within the policy. The ownership of a policy may be changed by asking the in-



insurance company to transfer ownership to another person. (This does not change who is insured under the policy).

There might be valid reasons to change policy owners. For example, if you need to apply for state or federal support (Medi-Cal, welfare) a whole life-universal life policy that has a cash buildup might disqualify you for such aid. If it does, you might think about transferring the ownership of the policy (by gift) to a family member, lover or other special person. **Before changing ownership** obtain advice from either your insurance company, agent, or lawyer, because the transfer may affect how the policy may be taxed. Remember, once a policy owner is changed the **new owner has all legal rights** to the policy, including naming the beneficiary and the ability to surrender or cancel it.

### **Beneficiary:**

The beneficiary of the policy is the person or estate that has been named in the policy. The owner may change the beneficiary at any time by notifying the insurance company, **in writing**, on the proper beneficiary change form. The company must record the change in their files for it to be effective. You may name anyone you wish as beneficiary, or more than one person may be named to share in the policy proceeds. Just list each name and the amount each beneficiary is to receive. A non-profit organization may be named also (such as AIDS Project/Los Angeles, National Gay Task Force, Shanti). If you name an organization be sure to use the legal name and include the address of the organization on your beneficiary forms.

It is important to remember that the insurance contract is just that, a contract. You cannot change your beneficiary through your will. A clause in your will saying that you want your benefits to go to your mother will not be followed if your policy says that your benefits are to be payable to your sister; (your sister would get the proceeds of your policy, not your mother).

### **Disability premium waiver:**

Look to see if your policy has this feature. If this provision is included in your policy and you meet the definition of disability, you may file to have future premiums waived (stopped) for as long as your disability lasts. Exercising this clause requires you to notify the company and file for the benefit. The only change that occurs in your policy is the elimination of premiums. It generally will not affect the death benefit cash values, but may affect future dividends.

### **Cash values/Dividends:**

An individual policy with cash values offers you a great deal of flexibility. Cash values (and dividends) can be borrowed from the policy to pay premiums, pay bills, or for any other reason. Several things occur if you borrow from the policy. The loan incurs a simple annual rate of interest (as stated in your policy loan clause). The interest charged is usually between five and eight percent. The loan and any accrued interest charges will be subtracted from any later death benefit while the loan is outstanding. You do not have to pay back the loan at any time. However, interest charges should be paid each year. If not paid, interest will be added to the loan amount each year increasing the loan balance.

If you cannot pay the premiums and are not eligible for the disability premium waiver benefit, then borrowing against the policy to pay the premiums may be an alternative to losing the coverage. Call or write the insurance company to determine what cash values you may have. (Be sure to include your name and policy number with any request for information on your policy.)

Dividends can be used to reduce your premiums. Dividends are a return of excess



premium in the policy. They can be taken in cash, left to accumulate in the policy, used to reduce the premium, or left to purchase additional death benefits. Any or all dividends can be taken out in cash, generally, without affecting the basic policy or its death benefit. Contact your agent or company to make sure that any change in your dividend status does not alter the basic structure of the policy.

Term insurance does not develop cash values, but it may pay dividends. These dividends can be used to reduce your premiums. Again, see if a disability premium waiver exists in the policy. Group life coverages seldom have cash values or dividends (there are some exceptions).

### **Grace period/Lapse:**

All individual policies have a 31 day grace period after the premium is due during which you can pay your premium. As long as the premium is received during this period, your policy will remain in force. If a premium is not paid during this time, it will go into a state of lapse (the policy will be cancelled). Most companies will allow a few additional days to receive the premium without question. If you are just a few of days past the grace period with your premium, call the company to find out if the premium can still be paid.

If the policy is a whole life type policy (i.e. it has cash values) and lapses, there are still two options available to you. One is extended term coverage, the other is reduced paid-up life coverage. Extended term insurance provides coverage for a period of time that is determined by your age and the amount of cash values in the policy. Your policy has a chart which tells you how long the coverage will be extended. This time period will usually be stated in months and days of coverage (several years of coverage may be provided).

After the time period has expired, the policy terminates.

Reduced paid-up coverage is when the amount of coverage is reduced and the policy is then made fully-paid up (less coverage with no further premiums needed). Reduced paid-up life coverage is determined by the amount of cash value in the policy and your age. You can determine the amount of reduced paid-up coverage by looking for the proper table in the policy. Both of these options will be affected by any policy loans you have against the policy.

**Remember**, before allowing a policy to lapse, with your current health problems you will not be able to apply for a new policy until you are fully recovered. (Insurance companies may require a 5 to 10 year wait after a person is "fully recovered" from a major illness before they will issue additional insurance.) You might see if a beneficiary, friend, relative or lover would be willing to help pay the premiums. You might alter how premiums are paid. Smaller, more frequent premiums may be helpful. If none of the above options are helpful, you might ask the insurance company to lower the amount of coverage. You will be reducing your premiums and reducing your coverage; some coverage is better than none at all.

### **Cash surrender:**

An individual life policy with cash values, dividends or both, can be surrendered for the cash built up in the contract. Ask your insurance company to determine what the surrender value will be. Any of the options discussed above would be preferable to reducing or dropping coverage you might not be able to later replace.

### **Cancellation:**

Except for non-payment of premiums, individual life policies cannot be cancelled by the insurance company. The current nature of your health is not cause for the insurance company to cancel the policy. One exception to this general rule is the incontestable clause.



## **Incontestable clause:**

If a policy is less than two years old and a claim is submitted to the company (either a death claim or a premium disability waiver), the insurance company has the right to investigate the original application and the medical history upon which they based their decision to issue coverage. They might contact all your doctors to make sure the information they received when you applied for coverage was accurate.

Minor omissions such as a cold or flu will not cause the insurance company to cancel or rescind the policy. Major omissions or any attempt to hide important known health problems (examples: recent history of high blood pressure, syphilis, stomach problems, etc.) could justify such an action. If the policy is over two years old, you are generally home free and clear.

## **Suicide:**

All individual policies and many group policies include a suicide clause. Companies may not pay a death benefit due to suicide if it occurs during the first two policy years. Refer to the group life insurance section below for special notations about group coverage as it relates to suicides. Some persons with AIDS have made an election to go "no code" if hospitalized ("no code" simply means that the hospital staff will not use heroic measures to keep the patient alive). "No code" is not considered suicide. If you are worried about this, you might contact your insurance company claims office and ask what their position would be.

## **Conversion of decreasing term insurance:**

Decreasing term insurance policies allows you to generally change your policy from a decreasing death benefit policy to a whole life policy with level (non-decreasing) benefits. This allows you to keep the amount of your current coverage from going down each year. It is often advisable to convert your policy when there is a change in your health that would prevent you from obtaining more coverage. If you convert your policy, the premiums will increase, but your coverage will not decline. Check with your company to see how your conversion rights might benefit you.

## **Group Life Insurance**

Group life insurance coverage is somewhat unique and certain areas need to be discussed. Again you need to have a copy of your plan in order to follow along. Obtain a copy from your employer if you don't have one.

### **Amount of coverage:**

Group life death benefits will usually be stated in dollar amounts, however, it might be set in relation to your salary (i.e. two times annual salary). Occupational classes (i.e. owner, manager, hourly employee) are sometimes used to determine the amount of group life coverage you have.

### **Beneficiary:**

When you started to work with your current employer you filled out your group insurance papers. At that time you listed a beneficiary for your group life coverage. Check with your employer to see that it is still listed the way you wish. Filling out a beneficiary change form is one way to make sure that your beneficiary is correct. Remember, you can name any person, persons or organizations you wish as beneficiary.

### **Disability or Termination of coverage:**

A disability or termination of employment can affect your group coverage. If either oc-



curs, you will need to check with your employer about your insurance. You may be eligible for a disability premium waiver (if one is included in your group policy). If not, you may be eligible for a group life conversion policy. There may be ways to keep the coverage in force by working with your employer (paying your employer for the premiums yourself). Check it out!

### **Conversions:**

All group life policies have a conversion clause in the contract. If coverage terminates because you are disabled (and your group coverage does not have a disability waiver feature), termination of employment, or layoff, you must be offered a conversion policy. You can apply for any whole life policy the group carrier offers as long as the amount of coverage is equal to, or less than the amount you had under the group policy. You must apply for your conversion policy within 31 days of your termination date.

Ask your employer or group carrier for information about your group life conversion rights. Any conversion policy you apply for is offered to you at the same price available to the general public, and there are no health questions on the application. Your converted policy does not include any optional benefits, such as disability premium waiver or accidental death (i.e. double indemnity).

### **Suicide:**

Some group life contracts will not pay a death benefit where the cause of death is suicide. There may (or may not) be a two year incontestable clause in your group policy as exists under individual life policies. See suicide section above for information relating to a "no code" request.

## **CONCLUSION**

Anytime you have questions about your policies/coverages you should seek appropriate counsel. Help should be available from your agent, insurance company, lawyer, employer or possibly from your local AIDS organization(s). In the greater Los Angeles area, help is available to those who seek the services of AIDS Project/Los Angeles.

This section is not intended to offer legal advice, but rather, to help you review and better understand your insurance coverage. Hopefully, you now have a better appreciation of your policy and know what areas you might need to check into further. Any concerns you may have about your coverage(s) should be discussed with an insurance knowledgeable person.

## **NOTES TO APPENDICES**

The appendices included in this section are guides that should be useful in helping you through the chores of dealing with your insurance policies.

Appendix 1 is a one page summary of your health coverages. This will allow you to look up any benefits in one place at any time. You will not have to go back through your entire insurance policy to check what is covered and for how much. It should be useful to have copies of this page made so you can give a copy to your health care providers. All of the information they would need to know would be on this page.

Appendix 2 is a sample guide to help you keep track of your insurance claims. You may change the form to fit your needs. The manner in which you will be billed for medical care varies from one provider to another and often gets very complex. By using this form or one you design, you will be able to track your claims.



[illegible]



## APPENDIX #2

### Summary Of Your Health Coverage — Important Information

Your Full Name: \_\_\_\_\_

Date Of Birth: \_\_\_\_\_

Social Security Number: \_\_\_\_\_

Your Address: \_\_\_\_\_

Policy Number — ID Number: \_\_\_\_\_

Insurance Co. Name: \_\_\_\_\_

Claims Address: \_\_\_\_\_

Tel. Number of Claims Office: \_\_\_\_\_

Name of person you usually  
talk to at claims office: \_\_\_\_\_

Employer's Name and Address: \_\_\_\_\_

Maximum Benefit: \_\_\_\_\_

Deductible: \_\_\_\_\_

Co-Insurance: \_\_\_\_\_

Stop-Loss Point: \_\_\_\_\_

Hospital Room &  
Board Rates: \_\_\_\_\_

Tel. Number: \_\_\_\_\_

# Days Limitations: \_\_\_\_\_

Intensive Care Rates: \_\_\_\_\_

Special Features  
or Limitations: \_\_\_\_\_

Psychological Benefits: \_\_\_\_\_

Limitations: \_\_\_\_\_

Insurance Company  
Home Office Address: \_\_\_\_\_



## TAKING CARE OF BUSINESS

### Legal Resources

More often than not, most of us overlook the details of preparing for our future — whether near or distant; and when a problem or crisis arises, we are poorly equipped to respond. The purpose of this chapter is to provide a basic framework and resources with which to handle the future.

It is possible that you may never have need for many of these services, and we hope that you do not. However, we find that it is easier to deal with legal matters while healthy and calm rather than in the face of illness, stress or time limitations. Use this as an opportunity to think through your current needs and those that might develop.

Certainly each person's needs are different. You may have experienced job or housing discrimination as a result of an AIDS diagnosis. If you believe this is true, you may wish to discuss the situation with your local AIDS organization or legal counselor. Other legal issues to consider include estate planning, certain types of "power of attorney" (a mechanism for assigning decision-making authority to a competent person of your choice), wills, and funeral arrangements. Some of these actions involve time limitations which state when they become effective or outdated. It is important to consider these and plan ahead. The following discussion provides a brief explanation of these issues. For more clarification, consult a legal counselor or AIDS organization.

An attorney can assist with important matters concerning the management of one's affairs during life. For instance, conservatorships and certain types of power of attorney may, depending on the state of residence, give a friend or relative the authority to make medical decisions when and if you are no longer able to do so. A similar provision empowers the person of your choice to make decisions concerning your assets. The selection of the proper legal device requires a thorough exploration of the problems involved. An attorney can also discuss the extent to which a patient can control his or her own medical treatment. Very rarely, hospitals have lawyers or ethicists on staff who can help with these decisions. A couple of other issues you might like to clarify or document include visitation rights in the hospital setting and living wills (documentation of your medical treatment wishes with regard to life saving measures).

Each person has estate problems which are unique to that person. It is necessary to consider not only desires concerning the disposition of one's estate after death, but also the tax consequences of such dispositions. It is necessary to review the manner in which assets (i.e. money, possessions) are held and to make informed judgments concerning the advisability of changing the form of ownership during life. It is necessary to coordinate the benefits of life insurance, retirement plans, and IRA accounts with other aspects of the estate plan. Sometimes it is possible to arrange one's affairs during life so that there is no need for probate proceedings after death, and sometimes, but not always, this can be done without adverse consequences.

These determinations require a careful look at all the facts involved. It is extremely important that a person planning his or her estate obtain the assistance of an attorney trained in this process. References to probate and estate planning attorneys can be obtained through local Bar Association referral services as well as volunteer organizations who make referrals to qualified attorneys capable of dealing with these problems on a totally or partially volunteer basis. (Many AIDS organizations provide such volunteer services.)

Collecting the proper information for one's lawyer is a critical part of the estate planning process. A form such as that provided by the San Francisco AIDS Foundation can be helpful. (See end of this section for sample.)



The following is a list of some of the materials you may need to provide to an attorney:

- (1) Copies of deeds to real property
- (2) Copies of securities
- (3) Copies of notes showing debts to or owed by the person desiring a will
- (4) Copies of ownership certificates of automobiles, boats, etc.
- (5) Copies of life insurance policies or certificates, retirement plans, IRA accounts, and their Beneficiary Statements
- (6) Copies of documents showing the exact manner in which bank and savings and loan accounts are held
- (7) An estimate of the total value of the estate and of the total amount of obligations
- (8) Information concerning one's preference for funeral and burial arrangements
- (9) Copies of prior wills

While it is true that a will properly signed may be upheld even if it is signed just before death, the least satisfactory way to develop an estate plan is to wait until the last minute. There are not only emotional reasons for taking care of these matters well in advance, but there are legal reasons as well, among which are resolving such questions as whether or not undue influence was exerted over the person making the will and whether or not such person had the mental capacity required by law to make these decisions.

It is a common perception that all one has to do to create an estate plan is to write out a will and sign it before witnesses (or if the document is already in one's own handwriting, to forego having witnesses sign). Sometimes this kind of self-help works; more often it does not.

If you want to ensure that your wishes and plans are followed, consult a knowledgeable attorney. Feel free to discuss your concerns with a social worker or your local AIDS organization to find out which services might be most helpful to you. These are issues which we should all consider.

The following brochure, "Getting Your Affairs in Order" is reprinted with the permission of the San Francisco AIDS Foundation with the cooperation of Bay Area Lawyers for Individual Freedom.



**FINANCIAL**

## Checking account

Bank: \_\_\_\_\_

Branch: \_\_\_\_\_

Acct. #: \_\_\_\_\_

## Savings account

Bank: \_\_\_\_\_

Branch: \_\_\_\_\_

Acct. #: \_\_\_\_\_

## Credit union

Branch: \_\_\_\_\_

Account #: \_\_\_\_\_

## Other

Certificates: \_\_\_\_\_

\_\_\_\_\_

Stocks, bonds: \_\_\_\_\_

\_\_\_\_\_

Retirement Accts.: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Real Estate: \_\_\_\_\_

\_\_\_\_\_

How title is held: \_\_\_\_\_

Loans to others: \_\_\_\_\_

\_\_\_\_\_

**INSURANCE COVERAGE**

## Health Insurance

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Agent/contact: \_\_\_\_\_

## Life Insurance

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Agent/contact: \_\_\_\_\_

## Disability Insurance

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Agent/contact: \_\_\_\_\_

## Auto/Home/other insurance

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Agent/contact: \_\_\_\_\_

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Agent/contact: \_\_\_\_\_

**Deficits**

Loans:

Mortgage: \_\_\_\_\_

\_\_\_\_\_

Car loan: \_\_\_\_\_

\_\_\_\_\_

Personal: \_\_\_\_\_

\_\_\_\_\_

Other: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**CREDIT ACCOUNTS/CARDS**

VISA/Mastercharge/other:

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

Dept. stores/gas cards:

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_



## DOCUMENTS

Will

Location: \_\_\_\_\_

Date: \_\_\_\_\_

## Rental/Lease Agreement

Location: \_\_\_\_\_

Deposits to be returned: \_\_\_\_\_

## Tax Records

Location: \_\_\_\_\_

## Real Estate Documents

Location: \_\_\_\_\_

### Safe Deposit Box

Location: \_\_\_\_\_

Location of key: \_\_\_\_\_

Who has access to box: \_\_\_\_\_

Vehicle Registration: # \_\_\_\_\_

Location of forms: \_\_\_\_\_

Vehicle License: # \_\_\_\_\_

Other Documents: \_\_\_\_\_

## MISCELLANEOUS

Possessions to be listed in your will that you would like special individuals to receive:

Item

Person's Name

Who has copies of this form?

## GETTING YOUR AFFAIRS IN ORDER A WORKSHEET

Your Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Social Security Number: \_\_\_\_\_

Birthdate: \_\_\_\_\_

### IN CASE OF EMERGENCY CONTACT

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: (h) \_\_\_\_\_ (w) \_\_\_\_\_

Nearest Relative:

Name: \_\_\_\_\_

Telephone: (h) \_\_\_\_\_ (w) \_\_\_\_\_

## RESOURCE CONTACTS

Employer: \_\_\_\_\_

Telephone: \_\_\_\_\_

Doctor(s): \_\_\_\_\_

Telephone: \_\_\_\_\_

Attorney: \_\_\_\_\_

Telephone: \_\_\_\_\_

Accountant/Bookkeeper: \_\_\_\_\_

Telephone: \_\_\_\_\_



## APPENDIX

- Resource Directory
- Glossary
- Flow Sheet for Keeping Data  
for Health Care Providers

### RESOURCE DIRECTORY

#### Section I

#### AIDS RELATED ORGANIZATIONS AND HOTLINES

##### BY STATE (U.S.)

##### ARIZONA

###### Phoenix:

Phoenix Hotline, (602) 957-0363

###### Tucson:

Tucson Alternative Lifestyle Health Association, P.O. Box 2883, 85702-2883, (602) 573-0096

Tucson Gay Health Project, P.O. Box 2807, 85720

Tucson Gay Men's Clinic, 101 W. Irvington Road, 85714

##### CALIFORNIA

###### Berkeley:

Gay Men's Health Collective, 2339 Durant Avenue, 94704-1670, (415) 644-0425

Pacific Center for Human Growth, 2712 Telegraph Avenue, 94705, (415) 841-6224 • (415) 548-8283

###### Garden Grove:

AIDS Response Program, Gay & Lesbian Community Services Center of Orange County,  
12832 Garden Grove Blvd., Suite 200, 92643, (714) 534-0862. Hotline: (714) 859-6482

###### Long Beach:

Long Beach AIDS Service Group, 2025 E. 10th Street, 90804, (213) 439-3948

Long Beach Department of Health, 2655 Pine Ave., 90806, (213) 427-7421, ext. 274

###### Los Angeles:

Aid for AIDS, 7985 Santa Monica Blvd., Suite 109-171, West Hollywood, 90046, (213) 461-6959

AIDS Project/Los Angeles, 937 N. Cole, #3, 90038, (213) 871-1284. Hotlines: (213) 871-AIDS, and  
(800) 922-AIDS (Toll-free for S. California only)

Gay and Lesbian Community Services Center, 1213 N. Highland Avenue, P.O. Box 3877, 90038,  
(213) 464-7400

People with AIDS — Los Angeles, c/o Trainor, 1752 North Fuller, 90046

Shanti Foundation, (213) 874-2030

South CA Mobilization Against AIDS, 1428 N. McCadden Place, 90028, (213) 463-3928

###### Sacramento:

Sacramento AIDS/KS Foundation, 2115 "J" Street, Suite 3, 95816, (916) 488-AIDS

###### San Diego:

Owen Clinic, University of CA Medical Center, 225 Dickinson Street, 92103, (619) 294-3995

San Diego AIDS Project, P.O. Box 81082, 92138, (619) 294-AIDS; Hotline: (619) 260-1304

Beach Area Community Clinic, 3705 Mission Blvd., 92109, (619) 488-0644

###### San Francisco:

AIDS InterFaith Network, 890 Hayes St., 94117, (415) 558-9644

AIDS Worried Well Group, Operation Concern, 1853 Market Street, 94103



Lesbian & Gay Health Services Coordinating Committee, Department of Public Health,  
101 Grove, 94102, (415) 558-2541  
People with AIDS/SF, 1040 Ashbury #5, 94117, (415) 665-3787.  
San Francisco AIDS Foundation, 54 Tenth St., 94103-0960, (415) 864-4376  
Shanti Project, 890 Hayes Street, 94117 (415) 558-9644

**San Jose:**

AIDS Foundation of Santa Clara County, 715 N. First Street, Suite 10, 95112, (408) 298-AIDS

**San Luis Obispo**

San Luis Obispo AIDS Task Force, 2180 Johnson Avenue, 93401, (805) 549-5540

**Quadri-Counties: (For Santa Barbara, San Luis Obispo, Ventura, and Kern Counties)**

Quadri-County AIDS Task Force, 300 San Antonio Road, Santa Barbara, 93110, (805) 967-2311, ext. 455

**COLORADO**

**Denver:**

Colorado AIDS Project, Gay & Lesbian Community Center of CO, 1436 Lafayette Street, 80218,  
(303) 831-6268  
Gay & Lesbian Health Alliance of Denver, P.O. Box 6101, 80206

**CONNECTICUT**

**Hartford:**

Hartford Gay Health Collective, 281 Collins Street, 06105, (203) 527-9813  
AIDS Coordinator, State Department of Health Services, 150 Washington St., 06106, (203) 566-5058

**New Haven:**

AIDS Project/New Haven, P.O. Box 636, 06503, (203) 624-2437

**DELAWARE**

**Wilmington:**

Gay & Lesbian Alliance of Delaware, P.O. Box 9218, 19809 (302) 764-2208

**DISTRICT OF COLUMBIA**

AIDS Education Fund, Whitman-Walker Clinic, 2335 18th St., N.W., Washington D.C. 20009,  
(202) 332-5295

**FLORIDA**

**Key West:**

AIDS Action Committee, Florida Keys Memorial Hospital, P.O. Box 4073, 33041

**Tampa:**

Tampa Bay AIDS, P.O. Box 350217, 33695-0217

**Ft. Lauderdale:**

Health Crisis Network, (305) 674-7530

**GEORGIA**

**Atlanta:**

AIDS Atlanta, 1801 Piedmont Rd., Suite 208, 30324, (404) 872-0600  
People With AIDS — Atlanta, c/o G. McGahee, 1235 Monroe Drive #1, 30306

**ILLINOIS**

**Chicago:**

AIDS Action Project, Howard Brown Memorial Clinic, 2676 N. Halsted, 60614, (312) 871-5777  
People with AIDS — Chicago, c/o Hall, 3414 N. Halstead Street, 60657  
Sable/Sherer Clinic, Fantus Health Center of Cook County Hospital, 1835 W. Harrison, 60612,  
(312) 633-7810



## **KENTUCKY**

### **Lexington:**

Lexington Gay Services Organization, P.O. Box 11471, 40511, (606) 231-0335

## **LOUISIANA**

### **New Orleans:**

Crescent City Coalition, Louisiana Community Center, 1022 Barracks Street, 60116,  
(504) 244-6900

## **MARYLAND**

### **Baltimore:**

Baltimore Health Education Resource Organization, Medical Arts Building/Read & Cathedral  
Streets, 21201, (301) 947-2437

Gay Community Center of Baltimore Health Clinic, 241 W. Chase Street, 3rd floor, 21201,  
(301) 837-2050

## **MASSACHUSETTS**

### **Boston:**

AIDS Action Project, Fenway Community Health Center, 16 Haviland Street 02115, (617) 267-7573  
Mayor's Task Force on AIDS, City Hall, Rm. 608, 2201

### **Dorchester:**

Haitian Committee on AIDS In Massachusetts, 117 Harvard Street, 02124

## **MICHIGAN**

### **Detroit:**

Palmer Clinic, 22750 Woodward, 48220

### **Royal Oak:**

Wellness Networks, Inc., P.O. Box 1046, 48068, (800) 521-7946, ext. 3582.  
Michigan: (800) 482-2404, ext. 3582

## **MINNESOTA**

### **Minneapolis:**

Minnesota AIDS Project, Lesbian & Gay Community Services, 124 West Lake Street, 55408,  
(612) 827-5614

## **MISSOURI**

### **St. Louis:**

AIDS Task Force, c/o Dept. of Anthropology, Washington University, 63130

## **NEVADA**

### **Las Vegas:**

Southern Nevada Social Services, P.O. Box 71014, 89109, (702) 733-9990

## **NEW JERSEY**

### **New Brunswick:**

New Jersey Lesbian & Gay Coalition, P.O. Box 1431, 08903

### **Trenton:**

New Jersey Department of Health, Division of Communicable Diseases, AIDS Office, Health &  
Agriculture Building, 08625, (609) 292-7300



## **NEW MEXICO**

### **Albuquerque:**

AIDS Task Force Hotline, (505) 827-3201  
Common Bond, P.O. Box 1191, 87131, (505) 266-8041

### **Espanola:**

New Mexico Physicians for Human Rights, P.O. Box 1361, 87532

### **Santa Fe:**

AIDS Task Force, P.O. Box 968, 87504  
STD Clinic, 605 Letrado, Santa Fe, (505) 827-9660

## **NEW YORK**

### **Albany:**

Capitol District AIDS, 332 Hudson Avenue, 12210, (518) 465-6094

### **Brooklyn:**

Haitian Coalition of AIDS, 255 Eastern Parkway, Brooklyn, 11238, (212) 783-2676

### **Buffalo:**

Buffalo AIDS Task Force, P.O. Box 38 Bidwell Stn., 14222, (716) 886-1274

### **New York City:**

AIDS Resource Center, 235 W. 18th Street, 10011, (212) 206-1414  
Gay Men's Health Crisis, Box 274, 132 W. 24th Street, 10011, (212) 807-6655  
New York AIDS Action, 263A W. 19th Street, Rm. 125, 10011, (212) 242-3900  
New York AIDS Network, 125 Barrow Street, 10014, (212) 206-1003  
Office of Gay & Lesbian Health, NYC Department of Health, 125 Worth Street, Room 604, 10013  
People with AIDS — NY, Box G27, 444 Hudson St., 10014, (212) 929-5741  
Wipe Out AIDS, 227 Waverly Place, 10014, (212) 675-1412

### **Rochester:**

AIDS Rochester, 1063 East Main Street, 14608

### **South Hampton:**

East End Gay Organization for Human Rights, P.O. Box 87, 11968

### **Stony Brook:**

Long Island AIDS Task force, School of Allied Health Professions, Health Sciences Center, SUNY, 11794, (516) 444-AIDS

### **White Plains:**

Mid-Hudson AIDS Task Force, Gay Men's Alliance, 255 Grove Street, 10601

## **NORTH CAROLINA**

### **Durham:**

AIDS Project, Lesbian & Gay Health Project, P.O. Box 11013, 27703, (919) 286-0079

### **Wilmington:**

GROW, A Community Service Corporation, P.O. Box 4535, 28406, (919) 675-9222

## **OHIO**

### **Cincinnati:**

Ambrose Clement Health Clinic, 3101 Burnet Avenue, 45229

### **Cleveland:**

Cleveland AIDS Foundation, 11900 Edgewater Drive, #907, Lakewood, 44107

### **Columbus:**

Open Door Clinic, 237 E. 17th Street, 43201, (614) 294-6337



## **OKLAHOMA**

### **Oklahoma City:**

Health Guard Foundation, 417 NW 9th Street, 73102, (405) 235-5693  
Oklahoma for Human Rights, 4107 East 2nd Place, 74112

## **OREGON**

### **Portland:**

Cascade AIDS Project, Phoenix Rising Foundation, 408 SW 2nd, Rm 407, 97204, (503) 223-8299  
AIDS Task Force, Good Samaritan Hospital, NW 23rd Street, 97210

## **PENNSYLVANIA**

### **Philadelphia:**

Philadelphia AIDS Task Force, P.O. Box 7259, 19101, (215) 232-8055

## **TEXAS**

### **Dallas:**

AIDS Task Force, Dallas Gay Alliance, P.O. Box 190712, 75219, (214) 528-4233  
The Holloway Foundation, 13777 N. Central Expressway, Suite 401, 75243, (214) 987-9023  
Oak Lawn Counseling Center AIDS Project, 3409 Oak Lawn, Suite 202, 75219, (214) 528-2081  
People With AIDS — Dallas, c/o Oak Lawn Counseling Center, attn: P. Gerber, 3409 Oak Lawn, Suite 202, 75219

### **Houston:**

Committee for Public Health Awareness, P.O. Box 3045, 77253, (713) 528-6333  
KS/AIDS Foundation of Houston, 1001 Westheimer, Suite 193, 77006, (713) 524-AIDS  
Montrose Clinic, 104 Westheimer 77006, (713) 528-5531

## **UTAH**

Hotline: (303) 831-6268

## **WASHINGTON**

### **Seattle:**

Seattle AIDS Action Project, 113 Summit Avenue E, #204, 98102, (206) 323-1229  
Seattle Gay Clinic, P.O. Box 20066, 98102  
Seattle-King County Department of Public Health AIDS Program, 1406 Public Safety Building, 98104, (206) 587-4999

## **INTERNATIONAL**

### **CANADA**

AIDS Committee of Toronto, c/o Hassle Free Clinic, 556 Church Street, 2nd floor, Toronto, Ontario M4Y 2E3  
AIDS Vancouver, c/o 19th floor, 355 Burrard Street, Vancouver, British Columbia V6C 2J3  
Centretown Community Resources, 100 Argyle Avenue, Ottawa, Ontario K2P 1B6  
Collective D'Intervention Communautaire Aupres des Gais, C.P. 29 Succursale Victoria, Montreal, Quebec, (514) 484-2602  
Comite SIDA du Quebec, 3757 rue Prud'homme, Montreal, Quebec H4A 3H8  
Gay Social Service Project, 5 rue Weredale Park, Montreal, Quebec H3Z 1Y5  
Gays of/Gais de Ottawa, Box 2919 Stn D, Ottawa, Ontario M5W 1X7

### **ENGLAND**

Capitol Gay, 38 Mount Pleasant, London, MC1XOAP

### **FRANCE**

Asociation des Gais Medecins, 45 rue Sedaine, 75011 Paris



## **THE NETHERLANDS**

AIDS Policy Coordinator, Jan K. van Wijngaarden, M.D., Buro G.V.O., Prins Hendriklaan 12, 1075 BB Amsterdam  
COC — Joop van der Linden, Rozenstraat 8, 1016 NX Amsterdam

## **PUERTO RICO**

### **Rio Piedras:**

Latin American STD Center, Centro Medico, 00922, (809) 754-8118

## **NATIONAL AIDS-RELATED ORGANIZATIONS**

American Association of Physicians for Human Rights  
American Psychological Association, 1200 17th Street, N.W., Washington, D.C. 20036, (202) 955-7600. Contact: Dr. Arnold Kahn  
Association of Lesbian & Gay Psychologists, American Psychological Association, 1200 17th Street, N.W., Washington, D.C. 20036, (202) 955-7600. Contact: Walter Batchelor  
Gay Nurses' Alliance, 608 W. 28th Street, Wilmington, DE 19802, (302) 764-2208. Contact: Jim Welch  
Gay Rights National Lobby/AIDS Project, P.O. Box 1892, Washington, D.C. 20012, (202) 546-1801  
National AIDS Hotline (CDC), (800) 342-AIDS  
National AIDS/Pre-AIDS Epidemiological Network, 2676 N. Halsted St., Chicago, IL 60614, (312) 943-6600, ext. 424, 389. Contact: David Ostrow, M.D.  
National AIDS Research & Education Foundation, 54 Tenth Street, San Francisco, CA 94013, (415) 626-8784  
National Association for Lesbian & Gay Gerontology, 271 Lacasa Avenue, San Mateo, CA 94403 (415) 349-4537. Contact: Donald Catalano  
National Coalition of Gay STD Services, P.O. Box 239, Milwaukee, WI 53201-0239, (414) 277-7671  
Contact: Mark Behar  
National Gay Health Coalition, 206 N. 35th Street, Philadelphia, PA 19143, (215) 386-5327.  
Contact: Walter Lear  
National Gay Health Education Foundation, P.O. Box 784, NYC, NY 10036, (212) 563-6313.  
Contact: Bernice Goodman/Ron Vachon  
National Gay Task Force, 80 Fifth Avenue, NYC, NY 10011, (212) 741-5800.  
Contacts: John Boring/Jeffrey Levi  
National People With AIDS Projects, c/o AID Atlanta, 1801 Piedmont Road, Suite 208, Atlanta, GA 30324, (404) 872-0600. Contact: Glenn D. McGahee  
Women's AIDS Network, 707 San Bruno Avenue, San Francisco, CA 94117, (415) 821-7984.  
Contact: Laurie Hauer

## **MISCELLANEOUS ORGANIZATIONS**

Many of these organizations are national in scope but may have local offices. Because of the distribution of this manual, the agencies listed here are primarily those in the Southern California or Los Angeles area. We suggest you contact your local agency through the telephone directory. Most local or county health departments have a contact person from whom you can get further AIDS information; that person is usually the infectious disease or V.D. control officer.

### **American Cancer Society:**

Los Angeles: 2975 Wilshire Blvd., Suite 200, Los Angeles, CA 90010-1110, (213) 386-6102  
National: 777 Third Avenue, New York, NY 10017, (212) 371-2900

**Centers for Disease Control**, 1600 Clifton Road, N.E., Atlanta, Georgia 30333

Community Cancer Control, 5410 Wilshire Blvd., Suite 1008, Los Angeles, CA 90036, (213) 938-2408

### **Gay/Lesbian Community Centers (check your local directory)**

Gay Community Center of Orange County, 12832 Garden Grove Blvd., Ste. 200, Garden Grove, CA 92643, (714) 859-6482



Gay and Lesbian Latinos Unidos, 1213 N. Highland Ave., Los Angeles, CA 90038, (213) 464-7400

Gay and Lesbian Coalition, P.O. Box 2055, Pomona, CA 91769, (714) 623-1491

Western Addiction/Gay Resource Center, 1128 De La Vina St., Santa Barbara, CA 93101  
(805) 963-3636

San Bernardino Gay and Lesbian Community Services Center, (714) 824-7618

South Bay Calif. Community Outreach Information Line, (213) 516-6998

Gay Center for Social Services, 1147 30th St., San Diego, CA 92102, (619) 232-7258

Unified Community Services Center, 2025 E. 10th St., Long Beach, CA, (213) 434-4455

Gay and Lesbian Crisis and Information Services of Ventura County, 1255 Callens Rd., #F,  
Ventura, CA 93003

**Hemophilia Center, Orthopedic Hospital**, P.O. Box 60132, Terminal Annex,  
Los Angeles, CA 90060, (213) 742-1000

**Hemophilia Foundation:**

So. California: 33 So. Catalina Ave., Pasadena, CA 91106, (213) 793-6192

National: 19 West 34th Street, Suite 1204, New York, NY 10001, (212) 563-0211

**Parents and Friends of Lesbians and Gays**, P.O. Box 24565, Los Angeles, CA 90024,  
(213) 472-8952

## **RESOURCE DIRECTORY**

### **Section II**

### **BOOKS, TAPES, AND REFERENCES**

This section lists several resources which may be helpful. It is certainly **not** exhaustive. For further resources, you may wish to contact a local counseling agency.

#### **PSYCHOLOGICAL SUPPORT**

**And a Time to Live**, Robert Cantor

Strategies and perspectives are presented to help people maintain or regain their sense of personal authority and competence during life-threatening illness.

**Anatomy of an Illness**, Norman Cousins

On healing and regeneration.

**The Will to Live**, Hutchnecker

A physician's observations of stress processes, disease, and return to health.

**When Bad Things Happen to Good People**, Harold Kushner

An attempt to help persons to cope with death and tragedy, particularly among the young. Written by a rabbi.

**You Can Fight for Your Life**, Lawrence Le Shan

A study of emotional factors in the treatment of cancer.

**Getting Well Again**, Simonton, Simonton and Creighton

Reviews research on the inter-relationship of the mind, body and disease processes. Outlines methods developed by the Simontons in the use of motivational psychology and imagery in combatting cancer. Encourages patients to take active part in changing feelings of hopelessness and depression.

#### **REGAINING HEALTH & STRESS REDUCTION**

**Holistic Way to Health**, Bloomfield & Kory

Range of practical ideas for improving health habits.



**Healing from Within, Jaffe**

How to work towards restoring and maintaining health by developing a healthier and less stressful lifestyle.

**Guide to Stress Reduction, Mason**

Survey of relaxation methods.

**Healing with Mind Power, Shames and Sterlin**

Use of hypnosis and self-hypnosis in improving health.

**NUTRITION****Eating Hints, National Cancer Institute Publication**

A guide to better nutrition during radiation and chemotherapy. Particularly helpful suggestions for boosting calories and taste. (Free) Available through: Office of Cancer Communications, National Cancer Institute, Bethesda, MD 20205

**When Eating Is a Real Jungle, Printed by Doyle Pharmaceutical company**

Provides practical suggestions for eating habits when you feel too ill to eat. Available through: Doyle Pharmaceutical Company, 5320 West 23rd Street, Minneapolis, MN 55416

(AIDS Project/Los Angeles has copies of both these materials for people with AIDS in Los Angeles County)

**AUDIO TAPES****Relaxation and Healing and Season for Health, Jaffe**

Relaxation and imagery as applied to cancer therapy. Available from: Learning for Health, 1314 Westwood Blvd., #107, Los Angeles, CA 90024

**Conditioned Relaxation, Bressler**

Available from: Center for Integral Medicine, P.O. Box 967, Pacific Palisades, CA 90272

**Stress Reduction First Aid Tape, Shealy and Halpern**

Step-by-step relaxation experience including relaxation/sleep induction. Tapes by Halpern include "Anti-Frantic Alternative" series. Available from: Halpern Sounds, 620 Taylor Way, #14, Belmont, CA 94002

A variety of instructive and purely music tapes for relaxation and stress reduction can be found at spiritual/psychological/environmental bookstores. Be creative and explore alternative resources.



## GLOSSARY

**ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)** — An acquired defect in immune system function which reduces the affected person's resistance to certain types of infections and cancers. Although the cause is unknown for certain, it is thought to be a virus (HTLV III) which is transmitted through intimate sexual contact or exposure to infected blood or blood products. AIDS has been termed the number one health problem in the United States by the U.S. Public Health Service. Once immune deficient, a person with AIDS becomes susceptible to a number of opportunistic diseases.

**ANTIBODY** — Protein molecules that are produced and secreted by certain types of white cells in response to stimulation by an antigen.

**ANTIGEN** — Any substance that provokes an immune response when introduced into the body.

**BACTERIUM** — A microscopic organism composed of a single cell. Many bacteria can cause disease in man.

**BASOPHIL** — A special white blood cell, called a granulocyte, filled with granules of toxic chemicals, that can digest microorganisms. Like the mast cell, its counterpart in the tissue, basophils are responsible for the symptoms of allergy.

**B CELLS** — White blood cells of the immune system derived from bone marrow and involved in the production of antibodies; they are also called B lymphocytes.

**BONE MARROW** — Soft tissue located in the cavities of the bones. Responsible for producing blood cells.

**CANDIDIASIS** — A yeast-like infection caused by *Candida albicans* which affects mucus membranes, the skin and internal organs. Oral infections are called thrush and exhibit creamy white patches of exudate on inflamed and painful mucosa. Common sites are the nailbeds, axilla, umbilicus, around the anus, the esophagus. It may occur systemically and affect the heart and the lining around the brain and spinal cord. This infection has become a standard problem seen in immune depressed people. It occurs frequently in the vaginal area where it is not associated with AIDS.

**CRYPTOCOCCOSIS** — An infectious disease being seen in AIDS patients which is acquired via the respiratory tract with a primary focus in the lungs and which characteristically spreads to the meninges (the lining of the brain and spinal cord) but which may also spread to the kidneys and skin. It is due to the fungus *Cryptococcus neoformans*. Meningitis with headache, blurred vision, confusion, depression, agitation or inappropriate speech is the most common form. It may be fatal.

**CRYPTOSPORIDIOSIS** — An infection caused by a protozoan parasite found in the intestines of animals. Once transmitted to man (by direct contact with the infected animal), it lodges in the intestines and causes severe diarrhea. It may be transmitted from man to man. While this infection seems to be occurring more frequently in immuno-depressed people, one study reports incidence in healthy persons as well.

**CYTOMEGALOVIRUS (CMV)** — A virus that is related to the herpes family; CMV infections may occur without any symptoms or result in mild flu-like symptoms of aching, fever, mild sore throat, weakness, enlarged lymph nodes. Severe CMV infections can result in hepatitis, mononucleosis or pneumonia even in non-immune suppressed men and 94% of gay men studied, but is usually mild and self-limiting. CMV is "shed" in body fluids — urine, semen, saliva, feces, sweat.



**DIFFUSE, UNDIFFERENTIATED NON-HODGKIN LYMPHOMA (DUNHL)** — A rare B-cell lymphoma that is difficult to distinguish from Burkitt's lymphoma. Its relationship to AIDS is uncertain at present and being investigated. The DUNHL patients exhibit generalized lymphadenopathy and enlarged spleens. This cancer is usually fatal.

**EOSINOPHIL** — A special white blood cell, called a granulocyte, that can digest microorganisms. Plays a role in allergic reactions.

**EPSTEIN-BARR VIRUS (EBV)** — A herpes-like virus that causes one of the two kinds of mononucleosis (the other is caused by CMV). It 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 the clearest link to date between viruses and cancer.

**FUNGUS** — Member of a class of relatively primitive vegetable organisms including mushrooms, yeasts, rusts, molds and smuts.

**GRANULOCYTES** — A cell of the immune system filled with granules of toxic chemicals that enable them to digest microorganisms. Basophils, neutrophils, eosinophils and mast cells are examples of granulocytes.

**HELPER T CELLS** — A subset of T cells that turn-on antibody production.

**HERPES SIMPLEX VIRUS (HSV I)** — The virus that results in cold sores or fever blisters on the mouth or around the eyes. Like all herpes viruses, the virus may lie dormant for months or years in nerve or lymph tissue and flare up again under stress, trauma, infection or immuno-suppression. There are no cures for any of the herpes viruses.

**HERPES SIMPLEX II (HSV II)** — Causes painful sores on the anus or genitals, but can be transmitted to the face or mouth.

**HERPES VARICELLA — ZOSTER VIRUS (HVZ)** — The varicella virus causes chicken pox in children and may reappear in adulthood as herpes zoster. Herpes zoster, also called shingles, consists of very painful blisters on the skin and follows nerve pathways.

**IMMUNE COMPLEX** — Large molecules formed when antigen and antibody bind together.

**IMMUNE RESPONSE** — The activity of the immune system against foreign substances.

**KAPOSI'S SARCOMA (KS)** — A tumor of the walls of blood vessels. Usually appears as pink to purple, painless spots on the skin but may also occur internally in addition to or independent of the skin lesions. Death occurs from major organ involvement. Originally seen in elderly men or in equatorial Africa as a slow growing, benign lesion, it is now occurring in young men, 80% of whom are gay, and is rapid and frequently fatal in its course.

**LEUKOCYTES** — All the white blood cells.

**LYMPH** — A transparent, slightly yellow fluid containing primarily lymphocytes. Lymph is composed of tissue fluids collected from all parts of the body and returned to the blood via the lymphatic vessels.

**LYMPHADENOPATHY** — Swollen, firm and possibly tender lymph glands. The cause may range from a temporary infection such as the flu or mononucleosis to lymphoma which is cancer of the lymph nodes. (Disease of the lymph nodes).

**LYMPH NODES** — Small bean-sized organs of the immune system, distributed widely throughout the body. An outpost for B lymphocytes.



**LYMPHOCYTES** — Small white cells, normally present in the blood and in lymphoid tissue, that bear the major responsibility for carrying out the functions of the immune system.

**LYMPHOKINES** — Powerful substances, produced and released into the bloodstream by T lymphocytes and capable of stimulating other cells in the immune system.

**MACROPHAGE** — A scavenger cell found in the tissues, able to destroy invading bacteria or other foreign material.

**MICROBES** — Minute living organisms, including bacteria, protozoa, and fungi.

**MICROORGANISM** — A microscopic plant or animal.

**MONOCYTE** — A large white blood cell which acts as a scavenger, capable of destroying invading bacteria or other foreign material.

**NATURAL KILLER CELLS** — Large granular lymphocytes that attack and destroy other cells such as tumor cells and those infected with viruses or other microbes.

**NEUTROPHIL** — A special white blood cell, called a granulocyte, that can digest microorganisms.

**OPPORTUNISTIC DISEASES** — Those diseases that are caused by agents that are frequently present in our bodies or environment but which cause disease only when there is an alteration from normal healthy conditions, such as when the immune system becomes depressed.

**PARASITE** — A plant or animal that lives, grows and feeds on or within another living organism.

**PERSISTENT GENERALIZED LYMPHADENOPATHY** — Chronic, diffuse, non-cancerous lymph node enlargement that has recently been found to be prevalent among gay men. It typically has been found in those with immune system disturbances who develop frequent and persistent bacterial, viral and fungal infections. The vast majority of people with this have not developed AIDS, as of this date.

**PNEUMOCYSTIS CARINII PNEUMONIA** — A lung infection seen in immuno-suppressed people. It is caused by a protozoa present almost everywhere but which is normally destroyed by healthy immune systems. It is airborne. Once a person develops PCP they are susceptible to reoccurrence of the disease and the outcome is often fatal.

**SUBUNIT VACCINE** — A vaccine produced from only part of an infectious agent.

**SUPPRESSOR T CELLS** — Subset of T cells that "turn off" antibody production.

**T CELLS** — White blood cells that are processed in the thymus. They produce lymphokines and are responsible, in part, for carrying out the immune response. They are also called T lymphocytes.

**T CELLS, helper/suppressor ratio** — T-cells are lymphocytes (white blood cells) that are formed in the thymus and are part of the immune system that has been found to be abnormal in AIDS patients. The normal ratio of helper T-cells to suppressor T-cells is about 2:1. This becomes inverted in AIDS patients because the number of helper cells is dramatically decreased.

**THYMUS** — A central lymphoid organ important in the development of immune capability.

**TOXOPLASMOSIS** — A disease due to infection with the protozoa toxoplasma gondii.

**VACCINE** — A substance containing the antigen of an organism which stimulates active immunity and future protection against infection by that organism.

**VIRUS** — Submicroscopic microbe causing infectious disease. Can reproduce only in living cells.



## SELF-CARE DATA FLOW SHEET

|                                                                      |  |  |  |  |  |
|----------------------------------------------------------------------|--|--|--|--|--|
| DATE                                                                 |  |  |  |  |  |
| TIME                                                                 |  |  |  |  |  |
| TEMPERATURE                                                          |  |  |  |  |  |
| SYMPTOMS:<br>Sweats (Y, N)                                           |  |  |  |  |  |
| Chills (Y, N)                                                        |  |  |  |  |  |
| Fatigue (Y, N)                                                       |  |  |  |  |  |
| WEIGHT                                                               |  |  |  |  |  |
| MEDICATIONS:<br>(Name, dose,<br>time taken)                          |  |  |  |  |  |
|                                                                      |  |  |  |  |  |
|                                                                      |  |  |  |  |  |
|                                                                      |  |  |  |  |  |
| FLUID INTAKE<br>(type, amt., &<br>Time)                              |  |  |  |  |  |
| URINE OUTPUT<br>(time & amt-S,M,L)                                   |  |  |  |  |  |
| DIARRHEA<br>(time & amt-S,M,L)                                       |  |  |  |  |  |
| FOOD INTAKE<br>Breakfast                                             |  |  |  |  |  |
| Lunch                                                                |  |  |  |  |  |
| Dinner                                                               |  |  |  |  |  |
| Snacks                                                               |  |  |  |  |  |
| COMMENTS:<br>(other symptoms,<br>visits to Dr.,<br>treatments, etc.) |  |  |  |  |  |



## SELF-CARE MANUAL EVALUATION QUESTIONNAIRE

This manual was produced with the needs of several interest groups in mind. In order to evaluate whether your specific needs have been met, please complete the following questions and return the questionnaire to:

Self-Care Questionnaire  
AIDS Project/Los Angeles  
937 N. Cole Avenue, Suite 3  
Los Angeles, CA 90038

A. Age \_\_\_\_\_

B. Sex \_\_\_\_\_

C. Ethnic Origin:

- ☐ White
- ☐ Black
- ☐ Hispanic
- ☐ Asian
- ☐ Native American
- ☐ Other

Sexual Orientation:

- ☐ Exclusively homosexual
- ☐ Predominantly homosexual
- ☐ Predominantly heterosexual
- ☐ Exclusively heterosexual

D. Reason for using manual (check all that apply):

- ☐ I have AIDS
- ☐ I consider myself at high risk of developing AIDS
- ☐ My lover/friend has AIDS
- ☐ A family member has AIDS
- ☐ I am a health care professional (specify) \_\_\_\_\_
- ☐ General interest
- Other \_\_\_\_\_

E. Rate the following questions with the number that most accurately reflects your response. Note additional comments on the back of the questionnaire. For each question answer:

- 1 — If you strongly agree
- 2 — If you somewhat agree
- 3 — If you are neutral
- 4 — If you somewhat disagree
- 5 — If you strongly disagree

1. \_\_\_\_\_ This manual improved my understanding of the medical and immunological perspectives of AIDS.
2. \_\_\_\_\_ This manual was well organized and easily understood.
3. \_\_\_\_\_ This manual provided me with the information I needed to take care of myself.
4. \_\_\_\_\_ This manual provided me with the information I needed to help someone else with AIDS.
5. \_\_\_\_\_ This manual has helped me identify sexual practices which increase which increase the risk of transmitting AIDS.
6. \_\_\_\_\_ The information in this manual has had an impact on:
  - (a) \_\_\_\_\_ my nutritional practices.
  - (b) \_\_\_\_\_ my approach to meeting my sexual needs.
  - (c) \_\_\_\_\_ my utilization of community resources.
  - (d) \_\_\_\_\_ my ability to cope with AIDS.
7. \_\_\_\_\_ As a result of reading this manual, my anxiety about AIDS has decreased.
8. \_\_\_\_\_ This manual has helped me with knowing where to turn for:
  - (a) \_\_\_\_\_ medical assistance.
  - (b) \_\_\_\_\_ religious counsel.
  - (c) \_\_\_\_\_ legal assistance.
  - (d) \_\_\_\_\_ psychosocial advice.



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