CHAPTER 3 HIV INFECTION AND AIDS: BASIC INFORMATION

Why the facts matter. What is AIDS? What is HIV? The effects of HIV infection. Using the right words. How HIV is and is not transmitted. Treatments, 'cures' and vaccines. The spread of AIDS worldwide. Living with HIV and AIDS.

WHY THE FACTS MATTER

As mentioned earlier, adopting an information-giving approach, which relies on 'expert' opinion is not an effective way to enable people to understand how HIV infection and AIDS fits into their lives. Also, factual information about HIV and AIDS is not always consistent, but rather changes as old theories are replaced by new ones. However, there are some important reasons why we need to understand some of the basic medical and scientific information about HIV and AIDS.

First, although theories are continually being developed and refined, we do now have a basic picture about the nature of HIV, the virus which can lead to AIDS, and its effects on the human body. Developing an understanding of the facts, then, is worthwhile since it enables us to understand future developments more clearly.

Second, young people often have many questions about the virus, how it is transmitted, and the ways in which HIV infection and AIDS affect the health of individuals. Furthermore, in working with young people it is likely that you will encounter substantial misinformation which they have gleaned elsewhere. It is essential, therefore, to have enough factual information at your disposal to be able to reply sensibly to questions asked, and to be able to counteract any misleading information, challenge prejudices and reassure against irrational fears and anxieties.

In order to do this, you do not have to become a medical 'expert'. Talking in complex medical terminology is not essential in HIV and AIDS education, indeed it is a disadvantage. What is valuable in the provision of information is the honesty to admit that you do not know everything, and the willingness to help young people find out more information for themselves. There are a number of books which will help if you need to find out more, and several periodicals are published which give regular updates on the latest medical and scientific developments. Further information can be found in Appendix G.

WHAT IS AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome, a phrase which actually tells us quite a lot in itself. It is important to stress that AIDS is a Syndrome, that is an aggregate of diseases and symptoms rather than a single disease. AIDS is usually diagnosed when someone has one or more of a very specific group of diseases, and has been infected with the virus, HIV. There are many disorders which can result in someone being diagnosed as having AIDS. But what links all of these is a Deficiency (that is, a failure or a malfunction) in one particular part of the body's Immune system. There are many reasons why part of the immune system could break down. Some powerful cancer-killing drugs, for example, damage the immune system. It is also possible to



be born with a genetic malfunction of the immune system (for example, the hereditary condition cystic fibrosis), which is why we need the word Acquired to describe AIDS, since the condition arises from damage to the immune system acquired as a result of infection with HIV, before or after birth.

HIV appears to damage part of the immune system which normally works very efficiently, so the conditions which affect people with AIDS are otherwise rare. One of them, a kind of pneumonia called PCP (Pneumocystis Carinii Pneumonia) was previously only seen in people whose immune system had been damaged during medical treatment, or as a result of great stress, such as people who had been in concentration camps during the Second World War.

Other opportunistic diseases include a form of skin cancer called Kaposi's Sarcoma (KS), although this is becoming less common as the epidemic progresses, infections such as toxoplasmosis and cryptococcosis, and brain diseases of particular kinds. The presence of one or more of these known disorders, of which there are over forty, plus the results of tests to determine whether or not the person has been infected by HIV, are all taken into account in making the diagnosis of AIDS. AIDS can also be diagnosed when symptoms appear showing that HIV is directly affecting certain organs.

WHAT IS HIV?

HIV stands for Human Immunodeficiency Virus. This is a virus which can cause a failure of part of the immune system in humans. HIV is not passed from animals to humans, like rabies, for example, because it is species specific.

Viruses are the smallest known living organisms. They are smaller than bacteria, and consist of a core of genetic material which carries the chemical 'programme' necessary for the virus to reproduce. This is surrounded by a coat of protein, which is then surrounded by a further protective layer, or envelope. Viruses come in a variety of shapes and sizes (although all are very small and cannot be seen with the naked eye), and cause all sorts of diseases, from 'flu' and herpes to some kinds of cancer. Because they are so simple, they cannot survive or reproduce by themselves, and need a 'host', such as plant and animal cells, in which they exist. They are usually very specialised, so that a virus which infects roses will not trouble cabbages, and a human with 'flu' will not give the disease to the family pet.

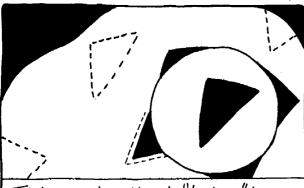
Like all viruses, for HIV to reproduce, its genetic material must enter another cell, and some of the cells it favours are found in the human immune system. In fact, HIV belongs to a very specialised family of viruses which are known as retroviruses, because in order to reproduce it must first knit itself into the genetic material of the cell it has infected. Not all viruses do this, and the problem with those that do is that they are very hard for either the body or anti-viral drugs to deal with, without destroying the cell itself. This is why it is so difficult to develop a 'cure' for HIV, since anything which damages the virus is also likely to damage the cell it has infected.



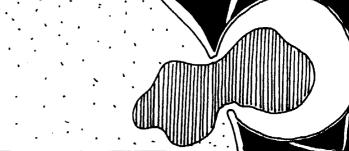
The outer shell of the immune system's T-cells have RECEPTORS, intended to enable the cell to latch on to the protein it needs

HIV has projections on its surface which exactly mimic the receptors on the T-cells





This enables HIV to lock on to the surface of the T-cell.

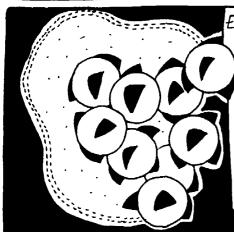


Once this has happened, genetic material from HIV passes through the outer shell and into the T-cell.

Here it begins to knit itself chemically

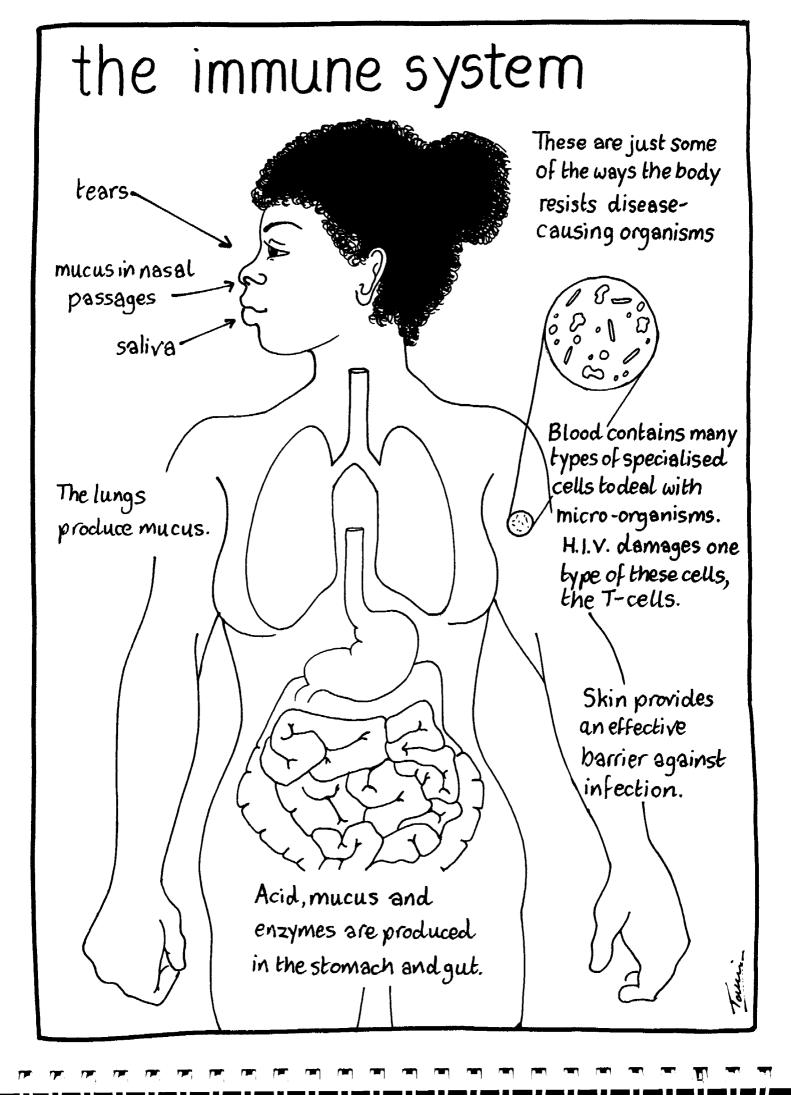
into the genetic material in the core of the cell, where it may remain dormant for months, or even years, ready to trigger the production of more virus in side the cell.

At this stage the person may not know they are intected. They may remain perfectly well, but they <u>NIU</u> he capable of <u>transmitting</u> HIY through sharing ditty needles or unprotected sex.



Eventually the T-ce'll dies, releasing new viruses into the bloodstream. They begin to 'latch on' to other T-cells

and as more and more T-cells become damaged, the immune system begins to weaken, and the person becomes ill.



THE EFFECTS OF HIV INFECTION

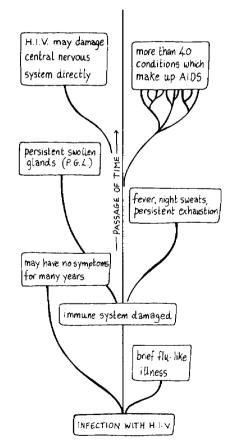
There are special substances on the outer surface of HIV which cause it to 'latch on' to certain kinds of white blood cells. Once this has happened, HIV's genetic material knits into the genetic material of those cells, where it may remain for some time (months or even years) before it triggers off the production of new viruses. By interfering with the cells which protect us against infection, HIV leaves the body poorly protected against the particular types of disease which these cells normally deal with. HIV only damages one particular component of the immune system, it does not destroy the entire system. It does not, for example, interfere with those parts of our immune system which have evolved to protect us from colds, so a person with HIV infection is not more vulnerable to all everyday illnesses.

The effect of HIV on the body comes from the damage it can cause to part of the immune system. The immune system is the means by which the body protects itself from possible infection and disease. We are protected by physical barriers such as the skin, as well as by specialised white cells in our bloodstream which deal with potentially harmful micro-organisms such as viruses. Some of these cells produce chemicals called antibodies which neutralise the infection. Others act in unison with one another to destroy bacteria and viruses more directly. There are many different kinds of white blood cell, and each type is specially equipped to protect us against different kinds of micro-organism.

After being infected by HIV, some people show no symptoms of disease and may be asymptomatic for months or even years. Others may develop one of the many conditions which make up HIV disease. The term HIV disease covers a broad spectrum of complaints: some of these are relatively minor whereas others are much more serious. AIDS is one of these possible consequences.

Shortly after being infected, some people experience a brief 'flu'-like illness lasting a few days. They may feel tired and develop a sore throat, and sometimes a rash appears. At about this time, the first antibodies to HIV are usually made as the body tries to protect itself. These antibodies are not powerful enough to neutralise the virus, a situation made more complicated by the fact that by now HIV will have already knitted itself into the genetic material of some white blood cells, ready to reproduce itself at a future date.

A relatively common complaint associated with HIV infection, is persistently swollen glands, usually in the neck and armpits. Doctors call this condition Persistent Generalised Lymphadenopathy (PGL). Swollen glands are relatively common in people who do not have HIV infection and can be caused by a variety of physical causes, and even stress, so a diagnosis of HIV infection can only be made once all other possible causes have been ruled out. PGL may occur following a long period without any symptoms, and it may or may not be accompanied by other symptoms, including fever, night sweats, aches and general fatigue.



POSSIBLE RESULTS OF HIV INFECTION

Other conditions may arise in the months and years following infection, and these do not follow the same pattern in all people. They include serious and unexpected weight loss, persistent diarrhoea, wasting of the muscles, and brain disease. There is some evidence to suggest that women infected with HIV are more prone to certain gynaecological problems, such as cervical cancer and persistent and recurrent attacks of vaginal candida (commonly known as thrush or yeast infection), which are far more virulent than those experienced by women who are not immuno-compromised, and which do not respond well to treatment. Brain disease may or may not be accompanied by changes in thought, movement and personality. As the immune system is increasingly damaged, these health problems become more serious and more difficult to treat.

Until recently, it was believed that co-factors such as drug abuse or stressful living were needed for someone with HIV infection to develop the symptoms which constitute a diagnosis of AIDS. But, it now seems that time alone is the major factor. Current estimates suggest that, eight to nine years after infection with HIV, approximately half of those infected will have a diagnosis of AIDS.

It is important to note here that while the vast majority of scientists and doctors agree that HIV is the virus which can lead to the development of AIDS, there are a few who argue that HIV is either not the cause of AIDS, or that the presence of HIV without the co-existence of some other, perhaps unknown factor or factors, is not sufficient in itself to lead to AIDS. Although this view is held by only a very small minority, it is nevertheless important to acknowledge the existence of such theories, since in our role as educators questions may arise about diverse and opposing views. Despite popular notions, science can rarely offer clear, certain and unchanging 'facts'. We need to acknowledge this when discussing scientific theories about HIV and AIDS with young people.

USING THE RIGHT WORDS

Much confusion is created by inaccurate use of language when talking about HIV and AIDS. Being infected with HIV and being diagnosed as having AIDS are actually two very different things, and this difference is an important one for health education.

In everyday conversation, and in the popular media, we often hear talk of the 'AIDS virus'. By now it will be clear that there is no such thing. For example, people diagnosed as having AIDS because of the presence of PCP have been infected by *two* entirely different things, HIV and another micro-organism, called pneumocystis carinii. The micro-organism has only been able to take hold because of the damage already done by HIV. The term 'AIDS virus' confuses a virus (HIV) with a syndrome (AIDS) of many different medical conditions.

Although it is obvious that the 'AIDS virus' is an inaccurate term, it is widely used. While educators should make efforts to ensure that they do not use the term, it is likely that some young people will continue to use it. It is important to allow young people to discuss issues openly and

freely without interruption or inhibition. We can however encourage the use of accurate and appropriate terms and lead by our example. Some terms however *must* be discouraged either because they generate prejudice and are very offensive to people living with AIDS, or because they confuse the issues so much that there may be a danger of young people misunderstanding risk.

People often talk of the 'AIDS test', as if one simple blood test could detect both HIV and the many infections and disorders that signal that someone has AIDS. There is no one test for AIDS, but there are tests for HIV.3 Some of these, called antigen tests, detect the presence of the virus itself. Others, called antibody tests, detect the antibodies which the body manufactures after infection. Antibody tests are by far the most frequently used when trying to detect whether someone has been infected. Because it may take up to three months for these antibodies to develop, people are often asked to wait before taking a test if they think they may have been at risk very recently. Indeed, a follow-up test three months after the first one may also be desirable in some cases.

The majority of people who test HIV antibody positive do not have AIDS. For these reasons, it is very important not to use the phrase 'AIDS test'. The term 'HIV test' or 'HIV antibody test' should be used instead. Someone who has had a test which reveals antibodies to HIV is often referred to as 'HIV antibody positive', or 'HIV positive' for short. It is important to stress that many people who are HIV antibody positive may not be aware of being infected, and may, in fact, be perfectly healthy for years, but they are still able to transmit the virus to others.

It is also important to use the right language when talking about people with AIDS. There are a number of terms in daily use which people with AIDS find unhelpful, if not offensive. They include 'AIDS victim', 'AIDS sufferer' and 'AIDS patient'. These terms reveal a great deal about people's fears and anxieties about illness, but they do not tell us much about what it is like to live with AIDS. The terms 'victim' or 'patient' should always be avoided as they serve to disempower anyone to whom they are applied, suggesting that he or she is powerless in the face of disease. This is inaccurate in the case of HIV infection and AIDS, where many people are actively fighting back, not only against the conditions themselves, but against widespread misunderstanding and hostility. The term 'sufferer' is best avoided for the same reasons, though this is not to deny the emotional and physical pain that may be experienced by people living with AIDS. The term 'People Living with AIDS', (which you may see abbreviated to PLWAs or PWAs) is the most appropriate one to use.

Another term which needs mention here is 'AIDS carrier'. This is usually applied, quite incorrectly, to those with HIV infection, but who have not developed AIDS. It conjures up medieval visions of plague and pestilence, and of infection by unwitting casual contact. As we have seen, having HIV infection and having AIDS are completely different things, and it is quite

HOW HIV IS TRANSMITTED

unnecessary to fear casual contact. The term 'AIDS carrier' implies that AIDS itself can be caught. It also creates the misleading impression that people with AIDS are somehow a 'threat' to others. Instead of 'AIDS carrier', a term such as 'someone with HIV' or 'someone with HIV infection' is more accurate and less offensive.

Finally, there is the term 'full-blown AIDS'. This tends to reinforce two untruths. The first is that AIDS takes the same course in all individuals, progressing towards one particular 'full-blown form'. As we have already seen, this is not the case. Secondly, it tends to imply that AIDS is the only long term consequence of being infected with HIV. This may or may not be true, we simply do not know. The only clear term to use is simply 'AIDS' which, as we have seen, refers to a wide range of different medical conditions.

It is now quite clear that HIV can be transmitted through infected blood and infected blood products, through cervical and vaginal secretions, and through semen. In order to be infected, there must be a way into the body, for example, the anus, vagina or an injection site. Sexually, it can be transmitted from man to woman, woman to man, man to man, and woman to woman through activities which involve penetration of the vagina or anus. In some cases, transmission may take place with the first sexual contact, in others even repeated sexual contact may not result in infection. It is not clear why this is so, though some doctors believe that people with HIV may be more infectious at some times than others. There is also some disagreement about how effective the mouth is as an 'entry point' for the virus. Although there is little doubt that oral sex, to a man or a woman, is safer than unprotected anal or vaginal intercourse, there is little agreement on how safe it is. Current advice is that unless there are cuts or sores in the mouth, oral sex is a safer sexual activity than intercourse, but that it is safer still if a condom or dental dam is used. Similarly, kissing, even when it involves the exchange of large amounts of saliva, offers very little risk.

As a virus which lives in blood, HIV can be transmitted through the sharing of syringes and needles, if one of those involved is infected. Because people with haemophilia need regular treatment with Factor 8, a product concentrated from the blood of many donors, many of them became infected with HIV before the virus was recognised. It is estimated that up to two-thirds of people with haemophilia in Britain may have been infected in this way. In Britain and many parts of the world, blood for transfusions is now routinely tested for HIV antibodies, and blood products used by people with haemophilia are heat-treated so as to inactivate the virus. Similarly, potential organ donors are now tested for HIV antibodies.

HIV can also be transmitted from mother to child before or around birth. Before birth, it may be transmitted across the placenta to the developing foetus, during birth it may be transmitted through the mother's blood, and afterwards there is some evidence for transmission through breast milk. It was initially believed that the risk of transmission from mother to infant was very high, but it is now known to be much lower.

HOW HIV IS NOT TRANSMITTED

TREATMENTS, 'CURES' AND VACCINES

Because HIV can live for such a long time in the body before symptoms appear, a changing pattern of those affected by it has been seen in the early years of the epidemic in the developed world. Initially gay men were the most affected, but new infections among injecting drug users and heterosexuals are now increasing. As people such as sex workers and gay men have taken action to prevent further transmission of HIV, the rate of new infection among these groups has slowed significantly, showing the effectiveness of safer sexual practices.

It is now absolutely clear that HIV is not transmitted through touch, coughing, sneezing, cutlery, glasses, cups and food, swimming pools, towels, toilet seats, pets, mosquitoes and other insects, baths and showers. If HIV was transmitted in these ways we would expect to find transmission taking place in all sorts of settings where people simply live closely together. This has not happened unless the parties concerned have been involved in a sexual relationship or have shared injecting equipment with one another. Likewise, there is no evidence for transmission via saliva, tears or perspiration. It is clear therefore that the vast majority of work situations pose no risk of infection. Only those such as nurses, who come into direct contact with those specific body fluids which harbour the virus, need to take special precautions, and for them, the steps that are usually taken to guard against more infectious viruses transmitted through these same fluids (e.g. hepatitis B) will be quite sufficient. However, despite reassurance, some people continue to have fears and anxieties about transmission through casual contact.

Everyday beliefs which suggest that all kinds of diseases can be transmitted through close proximity to an infected person have a long history, though relatively few diseases are actually so easily transmitted. Judgmental attitudes which suggest that certain kinds of people such as injecting drug users, gay men and prostitutes are morally 'contaminating' and should be avoided, have become confused with ideas about infectiousness. Tact, persistence and sensitivity is needed when working around HIV and AIDS to counter this.

In the space available, it is not possible to discuss in detail all the different kinds of treatment that are now available to people with HIV disease. It is important to note however, that although there have been many developments since the early days of the epidemic, there are still no 'cures' on the horizon. However, in the absence of a cure, some doctors and scientists believe that HIV may become a 'manageable' disease in the future, if treated early enough.

Treatments for people with HIV infection and people living with AIDS can be divided into three main types: antiretroviral drugs which affect HIV itself, and so slow down damage to the immune system; immunostimulants which bolster the immune system; and, those drugs which treat opportunistic infections.

AZT, or Zidovudine as it is often known, is used against HIV itself. It works by slowing down and interfering with HIV's capacity to reproduce itself, but does not eliminate the virus from the body. Although AZT is in wide use, particularly for people living with AIDS, it is still being investigated to find out more about how it might be used, and in what dosages, to the fullest effect. A major limitation of AZT is that it appears to become less effective after between eighteen months and two years of use.

Two other drugs, Dideoxycytidine (ddC) and Dideoxyinosine (ddI) are also being used by people intolerant to AZT, by those no longer benefiting from AZT, and in some cases in combination with AZT. Both these drugs are undergoing continuing trials. Other similar drugs are currently under trial in Europe and North America and some show relatively promising results.

An alternative approach involves producing drugs which interfere with HIV's ability to bind or 'latch' on to the white blood cells it usually infects. Some of these drugs may mimic the binding sites on the relevant white blood cells, attaching themselves to all the available 'latches' on the virus and thus preventing it from doing any harm. Other approaches are being developed so that in time it may be possible to use several drugs simultaneously to interfere with different stages in HIV's lifecycle. The hope is that combination therapy of this kind will eventually be able to slow down, or even halt, disease progression, enabling HIV to be 'managed', rather like diabetes.

Immune stimulating drugs, such as Alpha Interferon, aim to bolster the immune system against infection and tumours. There are many problems with the use of immunostimulants, principally because it is difficult to stimulate the immune system without also stimulating HIV infected cells. They are also known to cause some severe side effects.

There are however many drugs effective against the opportunistic infections associated with AIDS. Co-trimoxazole (Septrin), for example, is often used in the treatment of PCP, and there are drugs to deal with many of the other diseases that can arise in the course of infection. Clotrimazole or nystatin, for example can be used to treat the oral thrush that can develop in people with HIV disease, and anti-viral drugs such as acyclovir are effective against herpes which can recur when the immune system is sufficiently weakened. Problems can arise, however, because many of these drugs need to be administered in relatively large doses and serious and debilitating side effects are common.

Finally, there has been much discussion about the benefits of holistic therapy in relation to HIV infection and AIDS. This move towards alternative or complementary medicine is perhaps best seen as part of a wider process of empowerment in issues to do with health, as people are beginning to take a more active part in their own health care generally. Certainly, it has done much to challenge the general fatalism that otherwise surrounds AIDS. A variety of holistic therapies have been tried by people with AIDS and HIV infection, including acupuncture, homeopathy, spiritual healing, yoga and relaxation training. However little systematic evaluation

has taken place in relation to these approaches, although there are numerous individual reports which testify to their value.

Many holistic health practitioners advocate a balanced lifestyle if the capacity for self-healing is to be maximised. In order to enhance physical, psychological and emotional well-being, careful attention needs to be given to diet, exercise and rest. Eating a well-balanced diet makes sense when resisting serious illness, but many people with AIDS, forced to live on state benefits, find buying reasonable food a real struggle. Of course these kind of approaches and those offered by mainstream medicine need not necessarily be seen as alternatives. For some they may offer complementary strategies by which to maintain health and well-being. However, complementary therapies, with their focus on controlling our own health, do raise some important concerns. They tend to be overly individualistic, and some people who become ill may feel that they have 'failed' to adequately protect their health, and so blame themselves for being unable to 'self-heal'.

Until recently, there has not been much optimism about vaccines to protect against infection. Part of the difficulty is that there are many 'strains' of HIV. Even within the same person, the virus changes over time. The key involves finding some part of it which does not change, and triggering the production of antibodies which will neutralise that stable part of the virus. Work is proceeding on this, but suitable vaccines are likely to take many years to develop.

Just as HIV infection is not confined to any particular types of people, so it is not confined to any particular area. AIDS is an epidemic which has left few parts of the world untouched. We cannot estimate with complete accuracy the number of people infected with HIV or living with AIDS because of the long periods of good health which people with HIV infection have, variances in reporting of cases within and between different countries, and in some cases, mis-diagnosis. However, it is clear that different countries are experiencing different rates of HIV infection.

Certain parts of the world have been characterised as high prevalence areas for HIV infection. Most particularly, developing parts of the world such as Latin-America, South East Asia and Africa have been identified as having high and increasing rates of infection. It is important to note that in these parts of the world also, rates do vary considerably between countries. Africa has largely been presented in our mass media as an undifferentiated whole rather than a continent made up of many different countries.

Often statistics of HIV infection and AIDS from other, distant parts of the world are interpreted by people living in Britain as meaning that people in Britain and Europe are in some way safe from infection. The idea that some areas of the world are 'prone' to AIDS allows people to distance themselves from the risk of HIV infection, and it must be emphasised that HIV infection results from what people do rather than where they live.

THE SPREAD OF AIDS WORLDWIDE

LIVING WITH HIV AND AIDS

As we have seen, and contrary to popular belief, being HIV positive does not automatically lead to terminal illness and death. Nor do all people diagnosed with AIDS have the same experiences. The disorders which indicate that someone has AIDS are very varied: some affect the lungs, some the skin, some the gut and others the nervous system. This means that the experience of being ill as a result of AIDS can be very different for different individuals. What all may experience, distressingly, are similar reactions from other people - reactions such as fear, hostility and discrimination which come both from ignorance about the medical facts and from prejudice against gay men and the other minority groups who have been commonly linked with AIDS in the media and the public mind.

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People with HIV infection may remain well for years, or may experience some of the symptoms described previously. People with AIDS may have periods of serious and distressing illness, alternating with long periods of feeling well. They have to cope, practically and emotionally, with the knowledge that their condition is terminal, and they all have to deal with issues such as potential loss of paid employment, telling family, friends, children and partners, as well as arranging for medical care and other support they will need. The knowledge that there is as yet no cure for AIDS, combined with uncertainty of how much time is left to them, and how long they can expect to remain well, can be hard to cope with. Nevertheless, many people living with AIDS have extremely full and positive lives, responding to the challenge by sorting out priorities for themselves and starting to take control of the way they want life to be. The key is to think, not of 'dying of AIDS', but of 'living with AIDS'.

SUMMARY

Facts alone are not enough to enable people to make sense of AIDS and to take the necessary steps to protect themselves and those close to them from infection. However, it will be clear from this summary of basic medical and scientific information that an opportunity to gain a real understanding of the way the virus works is of great value. Once the nature of HIV is understood, it becomes evident that no one group of people is going to be exempt from infection. HIV does not discriminate between people, and is not interested in our sexual behaviour, the colour of our skin, or our politics; all it can respond to is the nature of the white blood cells it needs in order to reproduce. It also becomes clear that, as this tiny virus cannot survive independently, it is very easy to safeguard against infection. Unless we have vaginal or anal sex without using a condom, or share needles with an infected person, we are extremely unlikely to become infected. The important thing to remain aware of is that people may have HIV and be quite well for years. It is therefore important to assume that the possibility of infection exists, and take suitable precautions when faced with any potentially risky situation - to protect both ourselves and others.

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