

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.

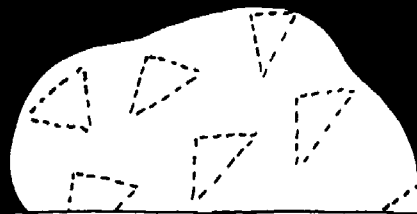
WHAT IS HIV?

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.¹ 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.

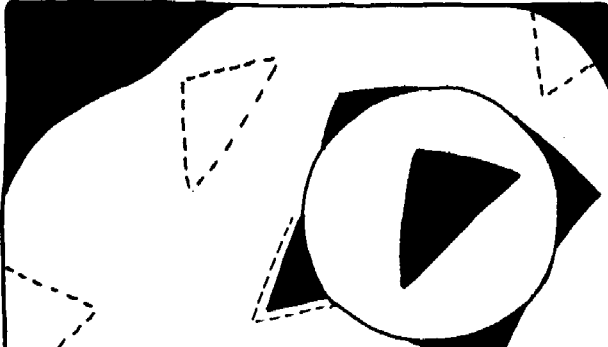
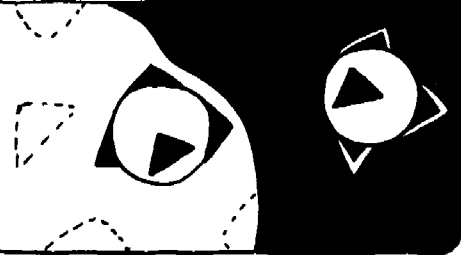
Like all viruses, for HIV to reproduce, its genetic material must enter another cell, and some of the cells it favours are found in the human immune system. In fact, HIV belongs to a very specialised family of viruses which are known as retroviruses, because in order to reproduce it must first knit itself 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.

Life cycle of H.I.V.

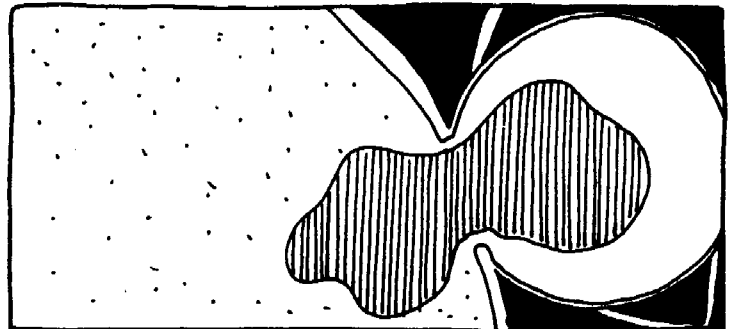


The outer shell of the immune system's T-cells have RECEPTORS, intended to enable the cell to latch on to the protein it needs

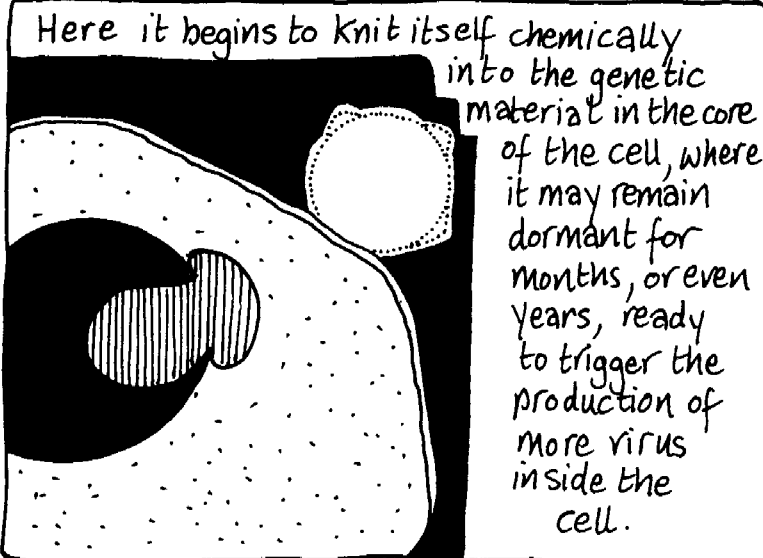
HIV has projections on its surface which exactly mimic the receptors on the T-cells



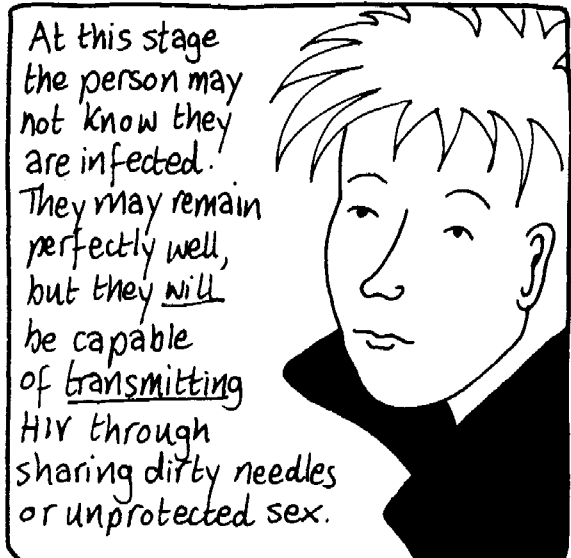
This enables HIV to "lock on" to the surface of the T-cell.



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



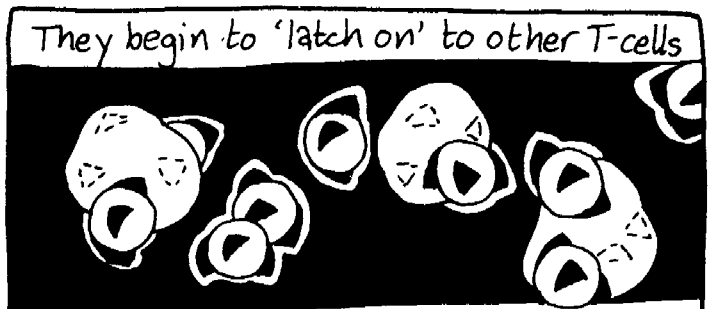
Here it begins to knit itself chemically into the genetic material in the core of the cell, where it may remain dormant for months, or even years, ready to trigger the production of more virus inside the cell.



At this stage the person may not know they are infected. They may remain perfectly well, but they will be capable of transmitting HIV through sharing dirty needles or unprotected sex.



Eventually the T-cell dies, releasing new viruses into the blood-stream.



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.

TAMARA

the immune system

These are just some of the ways the body resists disease-causing organisms

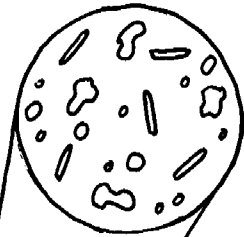
tears
mucus in nasal passages
saliva

The lungs produce mucus.

Blood contains many types of specialised cells to deal with micro-organisms. H.I.V. damages one type of these cells, the T-cells.

Skin provides an effective barrier against infection.

Acid, mucus and enzymes are produced in the stomach and gut.



Talwin

THE EFFECTS OF HIV INFECTION

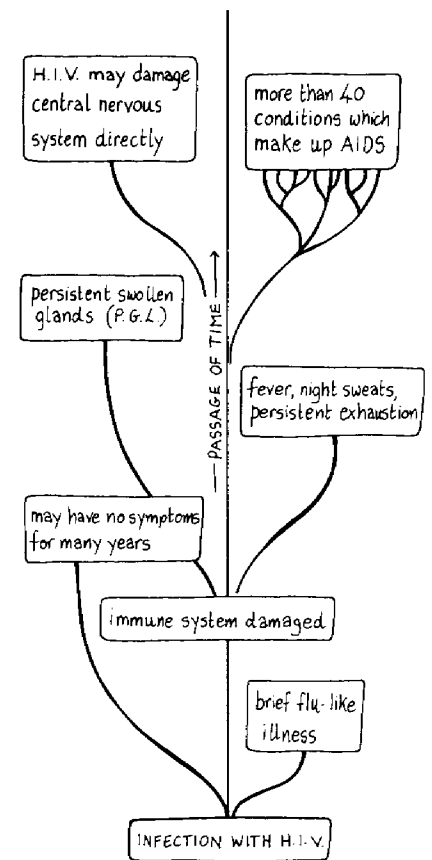
There are special substances on the outer surface of HIV which cause it to 'latch on' to certain kinds of white blood cells. Once this has happened, HIV's genetic material knits into the genetic material of those cells, where it may remain for some time (months or even years) before it triggers off the 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.

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

USING THE RIGHT WORDS

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.

