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Reference

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AIDS AND THE BLOOD

AIDS AND THE BLOOD has been written for members of the public with an interest in the donation and transfusion of blood. Prepared primarily for people with haemophilia and their families, the text contains factual answers to the many questions raised by recent reports on the care of those at risk from the acquired immunodeficiency syndrome.

Published at the Newcastle Haemophilia Reference Centre in association with the Haemophilia Society and the Terrence Higgins Trust.

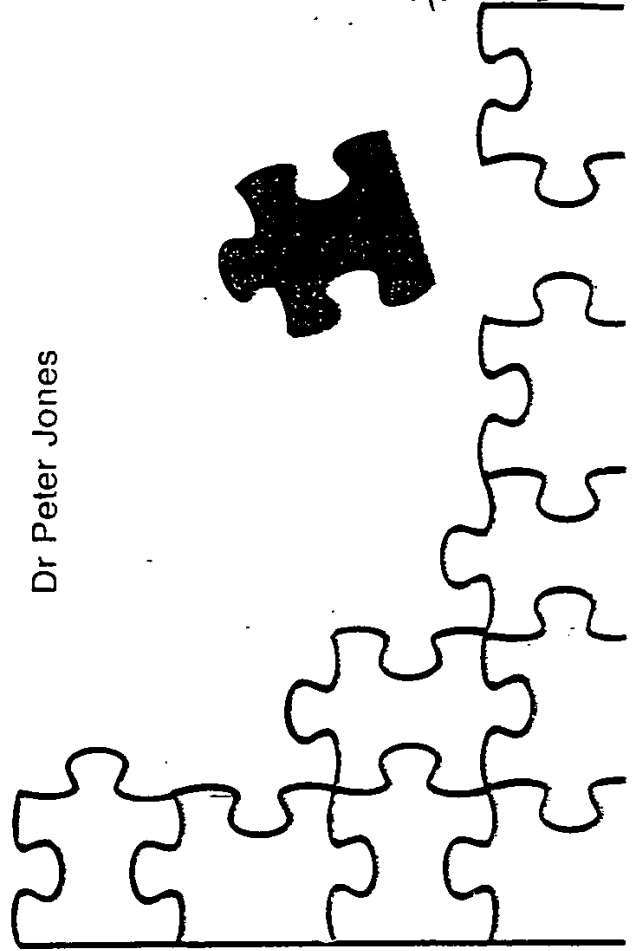
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A PRACTICAL GUIDE

Dr Peter Jones



AIDS hurts. It intrudes on the security and privacy of families. It attracts ill-informed, and sometimes cruel comment.

Faced with the possibility of AIDS people experience bitterness and anger. Sometimes denial of risk affords them protection. Sometimes anxiety or depression threatens to overwhelm them.

There is need for skilled help in coping with these, and with the other faces of AIDS. Practical help is based on knowledge, and in this booklet I have tried to give people something of our present knowledge of the disease. It has been written in response to the many questions asked by my patients and their families.

In reading it try to focus on the positive things you can do, both for yourself and for others. Above all, talk about it, and the questions it addresses. Talk with your family and friends, and never be frightened of seeking the advice of your doctor.

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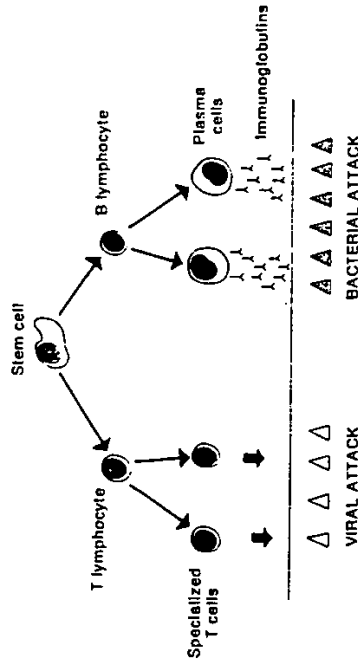
In acknowledging the great help I have received from colleagues, I hope that readers will understand that any errors or misconceptions in the text are entirely mine. Corrections and ideas for future editions are very welcome; an address is given on the inside back cover.

A.I.D.S.

AIDS

AIDS is short for the acquired immunodeficiency syndrome*. It is a relatively new disease, first coming to public notice in the United States in 1981. Its name suggests what happens in the body. The immune or defence system becomes defective, leaving the way open for potentially serious invaders which the body normally rejects.

The immune system is described more fully in the appendix (page 67). In brief what happens in AIDS is that one arm of our two armed defence system is affected. This arm is one in which cells called T cells are normally primed to repel invasion by viruses and other organisms. The other arm, in which cells called B cells work, is left relatively intact so most bacterial invasions are still repulsed.



CELL WARS:
the body's lymphocytes develop into two battle fleets to repel invaders. AIDS affects the T cell fleet.

Immunodeficiency itself is not a new concept to doctors. Occasionally children are born with incomplete immune systems; these are the babies who used to live in bubble tents to protect them from infection. Nowadays this protection may be given by injection of the necessary immune components. Far commoner are those patients in whom the immune system has been altered deliberately by medicines in an attempt either to control certain forms of cancer, or to help them accept a transplanted organ more readily.

*Sometimes written 'acquired immunodeficiency syndrome': 'Acquired' means that it is caught as an infection rather than inherited. 'Immune deficiency' means that the body cannot defend itself properly. 'Syndrome' means the illnesses that result.

As the story of AIDS has unfolded, numerous ideas about its origins and cause have been suggested. It seems that a virus, or family of viruses, present in the population of Zaire and surrounding countries in Central Africa was carried to either the United States or Haiti in the Caribbean in the 1970s, perhaps in a changed or mutant form. The virus is still active in Zaire, where it is presently epidemic in proportion, affecting both sexes.

The presence of the virus became obvious in the United States fairly quickly, both because it was spreading in a population with no natural resistance to it, and because it affected well-defined sections of the community in a country with excellent facilities for the monitoring of disease. Attention was first focused on male homosexuals and on addicts who abused drugs given by vein in New York City, and later on the West Coast of America, especially in San Francisco and Los Angeles. AIDS also appeared in Miami, a city with a high population of recent Haitian immigrants. The disease probably arrived in Britain around 1979. The first British AIDS case was diagnosed by 1981, and the first known death was in 1982.

From 1981, this spread was monitored closely by staff of the United States Public Health Service working from Atlanta in Georgia. They were able to trace contacts between affected people and to watch for other signs of the disease.

Early in its course in America it became apparent that AIDS was virtually confined to certain groups of people. The great majority of those with AIDS to date are male homosexuals (71%). Next commonest are people who abuse drugs by injecting them into their veins (13%) and people from or who have visited Haiti in the Caribbean (7%). People with haemophilia account for only 1% of the total, and people in whom there is a history of blood transfusion, in the absence of other risk factors, only slightly more.

As the numbers of haemophiliacs with signs of AIDS increased, it was suggested that there might be a link with the donation of blood plasma by male homosexuals or drug addicts harbouring the disease. This link was difficult to prove because no cause for AIDS could be identified, and so there was no specific test for the disease. However, the evidence was firm enough to encourage commercial companies involved in the collection of plasma to move their operations out of high risk areas, and screen out possible carriers.

What causes AIDS?

By 1983 obvious parallels between AIDS and hepatitis B (serum hepatitis) were becoming recognised and in that year a virus now called the human T-cell lymphotropic virus was discovered in the United States of America. The same year, a similar, if not the same virus, was isolated by workers in France. The Americans called their virus HTLV III (C) because it was the third in a series to be found. A test was developed which recognises whether or not a person has

been in contact with HTLV III. It works by recognising the antibody formed by the body as a result of this contact; someone may be HTLV III antibody positive, or HTLV III antibody negative. The test does not show whether a person has AIDS.

Present knowledge suggests that AIDS is just the most obvious part of a wide range of diseases linked to a family of viruses like HTLV III; the virus discovered in France is one of this family. The term 'HTLV disease' has been proposed to cover this spectrum of conditions and it seems that the relationship between HTLV disease and AIDS is very like the relationship between hepatitis and severe infection with the hepatitis B virus. In other words most people with HTLV disease suffer little or no illness as a result, although they may still be infectious to others, whilst a minority develop AIDS.

The present position

Although it has attracted a great deal of media attention, the AIDS problem is still small compared with other diseases. By January 1985 there were 7981 cases known in the United States, 59 of these were haemophiliacs and 112 were linked to blood transfusion. In the United Kingdom there were 118 cases of AIDS, principally amongst male homosexuals in London. Three people with haemophilia had AIDS. The figures are shown in the table.

However, HTLV disease is, as expected, much more prevalent. It has been estimated that in the United States some 300,000 people have been exposed to the virus. Estimates about how many will eventually develop AIDS vary widely. Present evidence suggests that haemophiliacs who become infected appear to be at a very much lower risk than infected male homosexuals. In Britain it is probable that several thousand people have been exposed. Only a few have been traced to African or Caribbean sources.

AIDS is frightening because it threatens people already under stress for other reasons, because it often has a long incubation period, because we cannot yet cure the full blown syndrome, and because the overall death rate is 47%. But this syndrome is rare, and present evidence is that the great majority of people exposed to the HTLV virus are not harmed by it.

	Total Population	Total AIDS cases	Transfusion Related	Haemophilic Population	Haemophiliacs
USA	216M	7981	112 (98 adult) (14 children)	20,000	59 (54 adult) (5 children)
UK	56M	118	0	4,500	3 (adult)

WHAT CAUSES AIDS?

At least one virus, possibly more, which are as yet unidentified.

The three front runners are called:

- human T-cell lymphotropic virus III (HTLV III)
- lymphadenopathy associated virus (LAV)
- AIDS associated retrovirus (ARV)

These viruses are probably variants of the same basic group. Collectively they have been called HTLV III(3) viruses by many workers. Using this term all the disorders associated with AIDS become 'HTLV disease'.

ARE THERE ANY TESTS FOR AIDS?

No diagnostic test for AIDS is yet available.

This means that it is not possible to tell a patient or his family that he has AIDS or not before the disease presents itself. This fact is of special importance to people who want to donate blood (see page 58).

The only tests presently of use to doctors are those which indicate changes in the body's immunity or defence mechanisms, and the test which indicates the presence or absence of the antibody to HTLV III (see page 6). The particular tests measuring changes in immunity will vary from clinic to clinic. Some can be performed on a blood specimen, some require the injection of substances into the skin in order to assess the body's response, or lack of it. The most widely used blood test is a count of the lymphocytes present in a drop of blood. In some hospitals the different types of lymphocytes are sorted and the numbers compared with one another (see page 68).

WHAT IS THE INCUBATION PERIOD?

On average, 28 months. The range is from 9 months to 6 years.

This time, between infection and disease, is known from the histories of those people who have developed AIDS following blood transfusion. However, even in this small group the range of probable incubation times is wide.

It has been difficult to determine incubation times in other at-risk groups because of the multiple exposures to the virus that are likely to have occurred. What is known is that a wide spectrum of response to the virus exists, from a very short incubation 'flu' like illness, through probable recovery, to very long times of up to 6 years.

WHAT ARE THE SYMPTOMS AND SIGNS OF AIDS?

The term 'symptoms' means feelings of ill health. The term 'signs' means recognisable features of disease. Because the fundamental fault in AIDS is loss of part of the defence system, invaders usually held at bay can gain access to the body. Hence many of the symptoms and signs associated with AIDS are simply those of infection.

They do not in themselves mean that AIDS is present, or that the person concerned is going to develop AIDS.

Both the Centers for Disease Control and the American Association of Physicians for Human Rights have listed the symptoms and signs found to be common before a diagnosis of AIDS has been reached. They are:

1. Profound fatigue, persisting for weeks with no obvious cause.
2. Unexplained weight loss (more than 10lbs in 2 months).
3. Drenching night sweats that may occur on and off for several weeks.
4. Fever lasting more than 10 days.
5. Cough lasting more than two weeks and not due to smoking. This may be associated with shortness of breath, persistent sore throat and difficulty in swallowing. The white spots of 'thrush' may be visible in the mouth.
6. Persistent diarrhoea.
7. Swollen lymph nodes ('glands') lasting more than a month.
8. Purplish or pink blotches in the skin (see page 12).

Each of these complaints can have many other causes which are of no consequence. The message is that because only a doctor can sort them out, anyone experiencing prolonged ill health and worried about AIDS should seek consultation quickly.

WHAT DISEASES ARE ASSOCIATED WITH AIDS?

There are 3 main categories:

1. Infections
2. Cancers
3. Other immune disorders

People with haemophilia A or B and AIDS have without exception been in categories 1 or 3. Only one cancer has been recorded in transfusion associated AIDS. That was a patient who had received fresh frozen plasma for factor V deficiency.

Infections

These are likely to be caused by viruses, fungi or parasites. Most bacteria are still repelled.

In haemophilia and AIDS the commonest disorder has been a parasite called *Pneumocystis carinii* (pronounced newmosis-ia caroni-eye), which causes a type of pneumonia.

The commonest fungal invader has been candida albicans, or 'thrush'.

The commonest viral invader has been herpes simplex, or 'cold sores'.

Other infections found with AIDS include unusually severe attacks of herpes zoster or 'shingles', toxoplasmosis, and tuberculosis, or tuberculosis-like disease.

Cancers

Two sorts of cancer have been found in AIDS patients other than haemophilics. One is called Kaposi's sarcoma. The other is a cancer of the lymphatic system called a 'lymphoma'.

Kaposi's sarcoma has been recognised in medicine since its first description by Dr Kaposi in the 19th century. Until AIDS came along it was found principally in Eastern Europe and Africa amongst the young male population. It was very rare in Britain, where it affected elderly people. It is a primary cancer of the skin, usually presenting as purplish blotches, which may be raised or flat. These blotches have been likened to 'bruises that don't go away'. They may appear in the mouth or nose, as well as in the skin.

A lymphoma usually presents as a swelling associated with the lymph nodes, or as a cancer of the white cells of the blood when it is called a leukaemia (leuk = white).

Other immune disorders

These have included a deficiency of blood platelets, called idiopathic thrombocytopenic purpura* (ITP), and a disorder in which red cells are destroyed prematurely called acquired haemolytic anaemia.

Both these conditions were well known to haematologists before AIDS and may well have nothing to do with the syndrome. ITP has certainly become more common in the haemophilic population, but is thought to be caused by immune mechanisms other than AIDS. Both conditions are curable in their own right by well proven treatments.

*idiopathic = cause not known, thrombocyte = platelet, purpuric = lack of, purpura = rash of red dots caused by minute bleeds into the skin.

CAN AIDS BE TREATED?

As yet there is no effective treatment for the underlying immune deficiency. Ways of stimulating the body's T-cells back into function are being explored, as are ways in which substitutes for them may be used.

Without immunity the patient becomes susceptible to infection. Most of the infections associated with AIDS can be treated, especially if they are detected early. However, experience so far is that most people with fully developed AIDS die within three years. Research on antiviral medicines might help change this gloomy picture.

HOW INFECTIOUS IS AIDS?

The virus or viruses that are thought to cause AIDS are not very infectious. They must gain entry to the bloodstream in order to cause damage. This is why AIDS is far more common among male homosexuals and people who abuse intravenous drugs than anyone else, and why a small number of haemophiliacs and other blood recipients have developed the disease.

Present evidence is that only a minority of people who are challenged by the AIDS virus(es) go on to develop the disease. In severe haemophilia one theory is that a small number of patients have been predisposed to changes in their immunity both by their genes and by frequent concentrate transfusion. Repeated challenge by an HTLV virus in this group then leads to AIDS.

See also page 51.

IS A PROTECTIVE VACCINE AGAINST AIDS AVAILABLE?

No.

Intensive research into finding protective medication against AIDS is under way, but no vaccine is yet available. Early indications are that effective vaccination will be difficult because of the behaviour of the virus in the body. However, even as this text is being written, the discovery of the genetic structures of the viruses found in America and France has been announced. Such is the speed of development in this field that nothing is impossible.

WHO IS MONITORING THE SPREAD OF AIDS?

Most countries have a system for the collection of information about disease, and the World Health Organisation (WHO) oversees developments on a global scale. The major place involved with work on AIDS is run by the United States Department of Health and Human Sciences in Atlanta, Georgia and is called the Centers for Disease Control (CDC). From here come regular updates on illness and causes of death within the USA, together with informed comment from experts.

In the United Kingdom the Communicable Disease Surveillance Centre of the Public Health Laboratory Service fulfils a similar role.

In addition to these government agencies many medical and voluntary organisations are involved with the dissemination of knowledge about AIDS. Among them are the United Kingdom Haemophilia Centre Directors, the World Federation of Hemophilia, which supports an office for the monitoring of AIDS in Los Angeles (World Hemophilia AIDS Center, WHAC), and many national haemophilia societies including the US National Hemophilia Foundation and the UK Haemophilia Society. In London the Terrence Higgins Trust, a charity named after the first British man to have died with AIDS, provides advice, education and support to anyone in need.

Addresses which may be useful are given on page 71.

IF I GET AIDS, WILL I HAVE TO GO TO A SPECIAL (VENEREAL DISEASE) CLINIC?

No.

Special Clinics exist to help people with illnesses that may have been transmitted sexually. Many people go to see the doctors in these clinics because they are worried that they may have contracted a sexually transmitted disease or may have harmed someone else by passing it on. Homosexuality as well as heterosexual people are welcome to seek advice, and because AIDS is commonest in the male homosexual community, clinical staff are used to coping with questions about it.

There may be circumstances in which their expertise is useful to patients with transfusion-related AIDS. Patients may want help in tracing sexual contacts, or need advice about their sexuality from staff other than those working in their haemophilia centre or local clinic.

The director of a Special Clinic may well be on the panel of experts advising on AIDS in your area. That does not mean that your name, or the details of your medical history will be known to him, or indeed to anyone else, unless you have given your permission.

IF I BECOME ILL, WHERE WILL I BE NURSED?

Whenever possible at home, just like anyone else.

If an infection is severe enough to require hospital admission the ward most suited to deal with the problem will be used. Most districts have hospitals with wards staffed by experts in the management of infection. Such a ward may be the obvious place to get the best possible treatment for one of the complications of AIDS.

IF I GET AIDS, HOW WILL I BE NURSED?

The guidelines of the Royal College of Nursing state that any precautions taken in caring for people with AIDS are "to minimise risk of infection to staff, while maintaining the dignity, integrity and privacy of the patient".

If you have to come into hospital you will probably be nursed in a cubicle of a general ward, or in a room in an infectious diseases ward. The precautions that are taken will be very like those already in use when nursing someone with hepatitis B, the aim being to prevent spread of infection to others. Staff will therefore wear gowns or aprons and gloves, may wear eye protection, and will take special care in the disposal of blood and body wastes. Visitors will, of course, be allowed. It is possible that those caring for you will have to wear masks. This precaution is taken to prevent infections reaching you, and will be determined by the type of illness you have.

Your family doctor and the district nurse will advise you and your relatives on what to do if you are ill at home. The main points to note are the need to dispose carefully of body wastes, and to prevent cross infection by having your own cutting and toilet utensils (see page 52). Disinfection with hypochlorite (bleach) will be explained (page 21). Linen and clothing used at home should be cleaned in the usual way in the domestic wash. Laundry contaminated by blood or body wastes may be washed separately in a washing machine at the highest possible temperature setting. In some areas the local health authority may have made special provisions for cleaning laundry for you.

If there is anything you do not understand in your treatment ask the nurse or doctor about it.

Not surprisingly people nursed in single rooms or cubicles often feel lonely and depressed. Your nurse will know this and will be able to help you, especially if you can talk about your worries. If depression gets too bad it can be treated effectively with medicines.

There is no special diet for people with AIDS. Patients may eat what they like and when they like and the more attractive and appetising the food the better. Alcoholic drinks are fine, but check with the doctor first to make sure they don't react with any medicines prescribed.

RECOMMENDED DISINFECTANTS

For routine cleansing of surfaces and soiled articles:

1. Hypochlorite solution containing 1,000 parts per million available chlorine; (1 in 100 dilution of 'Domestos').
2. Fresh 2% glutaraldehyde (Cidex); available only in hospitals.

For blood spills or gross contamination:

1. Hypochlorite solution containing 10,000 parts per million available chlorine; (1 in 10 dilution of 'Domestos').

Disposable gloves should be worn whilst using disinfectants.

HAEMOPHILIA

SHOULD I STOP MY HAEMOPHILIA TREATMENT?

No.

Bleeding causes more crippling and premature death in haemophilia than AIDS has or is ever likely to do.

When the AIDS scare started doctors caring for haemophilic families reassessed all forms of treatment available to them. For a while there was a cutback in the use of concentrates. Naturally, some people with haemophilia were reluctant to treat themselves with what they saw as a potentially dangerous blood product. Companies in the United States reported a 20 per cent fall in blood product consumption.

Once the dust settled fact began to impress itself again, and fact is that haemophilic bleeding has to be treated. However, modifications might be made, both to blood products and how they are used. These are described elsewhere (pages 26-33).

SHOULD I MODIFY MY HAEMOPHILIA TREATMENT?

You should certainly examine your treatment needs, or those of your child. Suggestions for the management of small children, and of those without severe haemophilia, are on pages 42-43.

If you have severe haemophilia think about the following, even if you have started heat-treated blood product:

- is the amount of factor VIII or IX you use in a year about average for your age and occupation? The doctor who advises you about your haemophilia will be able to tell you from knowledge of his own patients and the national figures. As a rough guide the average amount of factor VIII used per patient year in the United Kingdom is 34,000 units. Severely affected haemophiliacs, especially in the younger age groups, use more. Mildly affected older haemophiliacs use less.
- is most of your factor VIII or IX treatment being used to treat bleeds in one or two sites? If it is discuss other ways in which these bleeds might be managed with your doctor. For instance the inflammation of synovitis might be settled better by medicines than by more concentrate. Even surgery may require less concentrate than extended treatment for some recurrent bleeds.
- are you sure you are treating bleeds? Sometimes it is difficult to distinguish bleeding episodes from the discomfort or pain of arthritis. If you are not absolutely sure think about disobeying the rule 'if in doubt treat' for a while. You may have to suffer a haemarthrosis to find out, but on the other hand you may find you can reduce your treatment significantly without doing any harm.
- have you discussed prophylaxis recently with your doctor? In most cases prophylaxis is very necessary in order to prevent recurrent bleeds in a target joint (especially in haemophilia A) or almost all bleeds (especially in haemophilia B, Christmas disease). When used sensibly the amount of blood product used for prophylaxis is often less than that used to treat bleeding episodes 'on demand'.
- are you or your child overdoing things? Sports and active hobbies are vital to ensure health, especially in the younger patients. They help build muscle strength and bulk and protect joints. But think about reducing or changing an activity if you find it is linked with many bleeds.
- are you waiting for surgery? If you are, think about how necessary it is for your health and quality of life in the next year or so. Discuss it with your doctor. Are there alternatives which might not need such large amounts of blood product?

Whatever you decide, do not stop treating your haemophilia!

See page 25.

SHOULD I MAKE ANY CHANGES IN MY HOME THERAPY?

A few. We advise anyone other than the patient who is helping prepare or give treatment or cleaning up afterwards to wear disposable gloves, which will be provided.

This is especially important when they have cuts or abrasions of the skin.

Take extra care with needles. Never hurry any of the steps involved in mixing, drawing up and giving blood product. Check your equipment disposal routine (page 34).

Surfaces likely to be contaminated by blood or blood product should be covered with disposable plastic sheeting. Spillage should be wiped clean with sodium hypochlorite (bleach)*. If, for any reason, concentrate is drawn up into a syringe and not used it should be returned carefully to the bottle for disposal by the hospital.

Please keep all equipment out of the reach of children. Never allow syringes to be used as water pistols, even when new — the next syringe the child picks up when you are not looking may have been used for blood product.

Never re-use equipment.

Tell your doctor if anyone other than the patient has an accident with the equipment, especially a needle stick accident (pricked finger). See page 35.

These suggestions apply even if you are using heat treated blood product.

The question of dosage and treatment of bleeds is considered on page 26.

*Details of suitable disinfectants are given on page 21.

IS THERE ANY WAY TO TREAT BLOOD TO MAKE IT SAFE FROM AIDS?

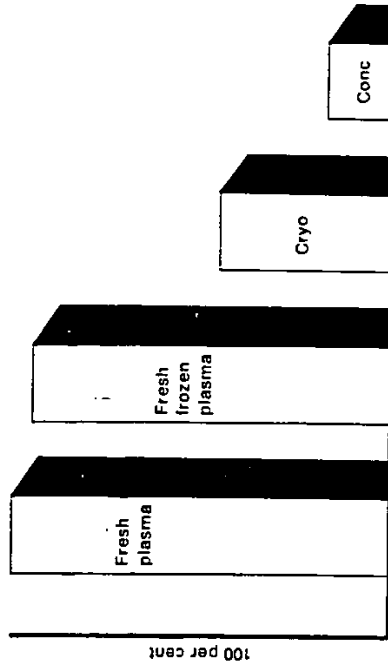
Some blood products can be heat treated in order to try and remove viruses. In the absence of a test for AIDS it has been difficult to determine how effective this is, but the early tests on the clotting factor concentrates have been encouraging enough to recommend their use (see page 31).

WHICH BLOOD PRODUCTS CAN BE HEAT TREATED?

In theory heat treatment can be used to try and reduce or remove viral contamination in all blood products not containing cells. This exception is because the cells are damaged by heat. Whole blood containing cells and red cells themselves are never warmed above body temperature during transfusion.

Heat treatment as a way of reducing the risk of infection in fluids is, of course, well tried and effective. The most obvious example is its use in the pasteurisation of milk. In transfusion too its use is by no means new. The plasma protein fraction called albumin which is widely used in medicine for the treatment of shock, is routinely heated to 60°C for several hours in order to remove the viruses that cause hepatitis (jaundice). Although the process does damage a small amount of this protein, this does not matter because it is safely and rapidly dealt with by the body.

Other products, including the clotting factor concentrates, are altered more profoundly by heat. Much depends on the temperature used, the duration of heating, the stage of the process during which heat is applied, and the stability of the proteins needed in the final product. For example, when factor VIII concentrate is heated in a dry form at least 15 per cent of its clotting activity is lost. When heated as a wet paste up to 50 per cent of the activity disappears. It might seem obvious to go for dry heating, but we cannot yet be sure which method is more effective in removing viruses, or which is less likely to damage other constituents of plasma.



As blood products become more refined the yield of clotting factor falls. Heat treatment reduces the clotting activity of concentrate even further (cryo = cryoprecipitate, conc = concentrate).

This damage and the possible side effects it might cause patients exposed to multiple transfusions was one reason why heat treated products were not prescribed widely before AIDS came on the scene. The other reasons were that:

- there was evidence that heating of clotting factor concentrates did not completely destroy the hepatitis viruses,
- because activity had been lost in the process, more donations of plasma were needed to make up the final product, and
- this pushed both the risk of exposure and the price up.

It is possible that the heat treatment of factor IX will increase side effects in a few patients to levels which are unacceptable. People using high doses of factor IX should discuss this with their doctors.

IS HEAT TREATMENT EFFECTIVE?

It is too early to be sure about this. Present knowledge depends on experiments in the laboratory. In these carefully controlled experiments in high security laboratories AIDS virus was added to clotting factor concentrate in known amounts. In a typical experiment cited by the Centers for Disease Control, AIDS virus was added to factor VIII concentrate. The concentrate was freeze dried as usual and then heated to 68°C (154°F). Virus was undetectable after 24 hours of heat treatment, the shortest time period examined. Tests on viruses of the same group as that believed to cause AIDS were also destroyed by heating. Future knowledge will depend on the results of following up patients using heat treated products, and on animal experiments.

As a result of these experiments CDC stated "The preliminary evidence concerning the effects of heat treatment on the viability of AIDS virus is strongly supportive of the usefulness of heat-treatment in reducing the potential for transmission of the AIDS virus in factor concentrate products and suggest that the use of non heat-treated factor concentrates should be limited".

This recommendation was adopted by the Medical and Scientific Advisory Council of the National Hemophilia Foundation, and subsequently by many doctors treating haemophilic patients. The NHF statement, published in their AIDS Update Medical Bulletin of 13th October 1984 reads:

"We do not yet have sufficient data of scientific nature to know with certainty that viral attenuated (heat treated) coagulation factor concentrates should now be universally adopted. However, very preliminary data do suggest that HTLV III is heat sensitive. Further, we do not know whether haemophiliacs who are positive for antibody to HTLV III have been exposed to living virus capable of causing AIDS, or have developed effective immunity against AIDS."

Because heat treated products appear to have no increase in unfavourable effects attributable to the heat treatment, we now recommend that treaters using coagulation factor concentrates should strongly consider changing to heat treated products with the understanding that the protection against AIDS is yet to be proven. We again urge a prospective national study of the use of these and other materials in patients not previously exposed to pooled blood products. In addition, further basic studies on the efficacy of viral attenuation procedures are urged. The Medical and Scientific Advisory Council will continue to review its position on heat treated products as more complete studies become available".

However, the laboratory tests have proved to be sufficiently encouraging to recommend that heat treated concentrates are used in preference to those that have not been treated.

DOES HEAT-TREATED CONCENTRATE COST MORE?

Yes. In Britain before heat-treated products were introduced the cost of a unit of factor VIII bought from a commercial company was between 8p and 9p. The cheapest heat-treated material is now retailing at 12p per unit. Most of the mark-up is because of the loss of yield caused by heating (page 29). The cheapest heat treated factor IX is being introduced at 13p per unit.

In a year the average usage of factor VIII per haemophilic in the United Kingdom is about 34,000 units. Pre heat-treated annual cost for concentrate for a haemophilic was therefore £2,720; using heat-treated material raises this to £4,080.

This cost still compares favourably with the costs of other chronic disorders which require regular therapy, for instance renal failure (£6,500 for the cheapest type of dialysis). It is salutary to note that it now costs local authorities £6,000 to care for someone in an old people's home for a year.

When assessing the economics of medical care it is important to remember that the benefit of the treatment usually outweighs its cost, both in terms of earnings and productivity, and in terms of quality of life which often includes caring for a family.

ARE THERE OTHER WAYS IN WHICH BLOOD PRODUCTS MIGHT BE MADE SAFER?

Exposure to ultraviolet light, to chemicals and to profound cooling have all been used in the attempt to destroy viruses in blood. None have been both totally effective and safe. For instance, even when red cells are stored in liquid nitrogen, hepatitis (jaundice) virus survives.

The chemical thought to be most effective in the destruction of viruses is called beta (B)-propiolactone. B-propiolactone is already used in combination with UV light during the preparation of some blood products in Germany. However, its safety is still considered as doubtful by some agencies, notably the Food and Drugs Administration in the United States. Until we know more it cannot be considered as an answer to the problem of AIDS and blood.

HOW SHOULD I DISPOSE OF USED HOME THERAPY EQUIPMENT?

If you are not sure of the local arrangements for safe equipment disposal make sure to ask the haemophilin centre staff as soon as possible. Everyone on home therapy will have been taught about the risk of spreading hepatitis by not disposing of needles, bottles and dressings properly. The only additional precaution to be taken because of AIDS is to wear gloves whilst clearing up if you are not the patient. After covering the injection site with a dressing, make sure to check the following straight away:

- **CAREFULLY** place all needles, including the small-vein set, in a needle ('sharps') disposal box.
- **NEVER** let this box overflow.
- **NEVER** force needles down into equipment discarded previously.
- **NEVER** bend needles after use. Discard needles straight into the disposal box; **DO NOT** reinsert into their original sheaths before discarding.
- Put syringes, bottles, used dressings, disposable sheets, and, last of all, your gloves into a plastic bag. Seal the bag.
- Wash your hands carefully with soap and water.
- Used equipment should be incinerated. It is much safer to return everything you use, properly sealed, to the hospital for incineration rather than to use an open fire at home.
- **NEVER** dispose of used equipment in your ordinary, household refuse collection as this may expose the bin-men to contamination.

These rules apply even if you are using heat treated blood product.

Advice on what to do with soiled clothing is given on page 20.

WHAT DO I DO IF I HAVE A NEEDLE STICK ACCIDENT?

If you are a haemophilic who has already had clotting factor concentrates, accidental puncture of your own skin with a needle exposes you to no additional risk. Simply wash the puncture site with antiseptic and cover it with a waterproof dressing for 2 or 3 days. Report any sign of inflammation around the puncture to your doctor. Obviously, if the accident results in a bleed you should treat yourself in the usual way.

Anyone other than a haemophilic who accidentally punctures their skin with a needle should:

- encourage bleeding from the puncture site, then
- wash the site liberally with soap and water, then
- swab the site with antiseptic and cover it with a waterproof dressing, and
- report the incident to their doctor within 24 hours.

This advice applies to any needle used for the preparation, drawing up or giving of blood products, as well as any needle that has entered the skin of someone with haemophilia, for instance a needle discarded after failed venopuncture.

The chances of contracting an AIDS related disease following accidental exposure by needle stick are very remote. One case involving a nurse has been reported in the *Lancet*. Although no specific antidote can be given following exposure your doctor may recommend an injection of a specially prepared immunoglobulin which helps boost the body's defence mechanism.

The possibility of a needle stick should alert everyone using blood products, especially clotting factor concentrates, to the need for special caution in both the giving of treatment and the disposal of used equipment. Whenever possible a haemophilic should give his own treatment. Please read the section on disposal (page 34).

DOES AIDS HAVE ANYTHING TO DO WITH CLOTTING FACTOR ANTIBODIES (INHIBITORS)?

No.

People with inhibitors are no more likely to develop AIDS than anyone else.

There is no evidence that the heat treatment of concentrates predisposes someone to the development of clotting factor inhibitors.

The presence of FII, V III antibody or AIDS does not predispose someone to the development of clotting factor inhibitors.

AM I ALONE IN FEELING DIRTY AND DEPRESSED ABOUT MY TRANSFUSIONS?

Not at all. It is a fact of life that no one chooses to be dependent on someone else for their health. But it is also a fact of life that people with haemophilia need treatment, that this treatment is only presently available from human blood, and that in most countries some of this blood has to be prepared from commercial sources.

Many haemophiliacs will remember earlier concerns about drug addicts being encouraged to sell their plasma. Publicity about this was at times so strident that some patients began to worry that the addiction itself could be spread by blood. This cannot, of course, happen. Neither can homosexuality be spread by blood.

Before AIDS appeared some of the plasma used to make factor VIII and IX concentrates in the United States was collected from communities with a higher than usual population of male homosexuals, and drug addicts and their heterosexual partners. As soon as a link between blood transfusion and AIDS was suggested the companies collecting plasma moved their operations out of New York, and the California cities concerned. As the link became firmer they began to ask people in the high risk groups to refrain from blood and plasma donation. In 1983 the UK Blood Transfusion Services did the same. A new leaflet for distribution to blood donors is being prepared.

HOW IMPORTANT IS FOLLOW-UP?

Vint.

Firstly, because only regular health checks of people at risk can reveal early evidence of illness. AIDS itself does not kill, infection does. The earlier the types of infection associated with AIDS are found the better the chance of successful treatment. This is especially so in haemophilia where the major infective problem has been pneumocystis carinii pneumonia (see page 12).

Secondly, because only by regular consultation with your medical advisers can you have your personal questions answered in the light of up-to-date knowledge. Advances in our understanding of AIDS result in continued upgrading of our advice to patients and families and this advice is passed on best in the privacy of a consulting room.

Thirdly, because one of the major ways by which we can learn about AIDS is to follow up as many people in the at risk groups as possible. As new tests for AIDS are developed they can be applied and assessed more quickly and accurately if follow-up is already assured.

WHAT ARE THE RISKS IN PASSING AIDS ON TO A HETEROSEXUAL PARTNER?

Very small, but there is a definite risk.

ITLV III disease has now been reported in the female partners of three haemophiliacs, and in the baby of one couple. This infection was probably acquired during pregnancy.

Knowledge of heterosexual spread in the African population, and in the United States and Caribbean strengthens advice about protection. We recommend that sexual intercourse is protected by condom (sheath) even when other contraceptive measures are being used by a couple. Genital contact itself is unlikely to transmit AIDS, but when the virus is present in semen the ejaculate will be infectious. Couples having oral sex should be aware of this.

For the moment semen from men who have received multi-donor transfusions in the past few years should probably not be used for the purposes of artificial insemination.

Because of the evidence from male homosexuals, rectal sex with a woman should be avoided.

SHOULD THE PARTNER(S) OF SOMEONE WITH HAEMOPHILIA BE FOLLOWED UP TOO?

Heterosexual relationships with multi-transfused people are at very little risk. At present there is no need to subject girlfriends and spouses to the worry and embarrassment of medical intervention unless, of course, they themselves would like reassurance. However, they should be aware of the recommendations about precautions during intercourse and advice on deciding whether to have a child (pages 39 and 41).

Whilst testing for HTLV III antibody in multi-transfused haemophiliacs some doctors are asking partners if they would mind being included too. This seems sensible as the more information that can be collected at this stage the better the accuracy of our counselling is likely to be in the future.

When someone with haemophilia presents with any of the conditions associated with AIDS we think consultation with partners becomes more important, and arrange to follow up all sexual contacts.

Follow up may be arranged by family doctors or by those concerned at the haemophilin centre or other hospital or special clinics depending on the circumstances. Our practice is to offer follow up in the centre. It includes regular physical check-ups, laboratory testing, and the opportunity to talk, and to ask questions in private.

WHAT ABOUT STARTING A FAMILY?

If the prospective father has received concentrates from multiple donations in the past few years he and his partner should talk to their doctor about this. So much depends on individual circumstances that it is impossible to give an answer which applies to every couple. In general terms, and with the knowledge of the remote risk of infection in the womb (page 39), it seems sensible to delay a pregnancy until we know more about AIDS and how to control it.

WHAT ADVICE IS BEING GIVEN TO PEOPLE WITH BLEEDING DISORDERS OTHER THAN SEVERE HAEMOPHILIA?

People with moderate or mild haemophilia A or B (Christmas disease) or von Willebrand's disease may respond to the treatments listed below. Although the use of these is recommended in preference to clotting factor concentrates, circumstances might dictate otherwise. For instance someone with moderately severe haemophilia B may require factor IX concentrate because the volume of fresh frozen plasma required to stop his bleeding may threaten to overload his circulation.

Alternative methods of treatment are:

1. blood products other than multi-donor concentrates
 - fresh frozen plasma. Obtained from individual volunteer donors. Contains all clotting factors including VIII and IX. Main disadvantage is difficulty in achieving high enough levels of clotting activity in the blood without overloading the circulation.
 - cryoprecipitate. Obtained from individual volunteer donors, then pooled. Average treatment in an adult requires 10 donations. Does not contain factor IX. Main disadvantage is requirement for storage deep frozen. In some countries heat treated concentrate may be safer than cryoprecipitate.
 - porcine factor VIII. Made solely from the blood of pigs, this is strictly a concentrate but is free of AIDS risk. Unfortunately it is usual for people to stop responding to porcine VIII within a week or so. Its major use is in the treatment of haemophiliacs with antibodies (inhibitors).

2. medicines

- desmopressin (DDAVP; deamino-D-arginine vasopressin). Only effective in people who can already make some factor VIII themselves, i.e. mild haemophiliacs or those with von Willebrand's disease.
- 3. — local haemostats are not usually effective although a few drops of Cyklokapron in the affected nostril may stop a nose bleed. The use of medicines like Cyklokapron, Epsikapron, or Amicar (antifibrinolytics, which stop clots breaking down) will often reduce the need for repeated blood product transfusion, especially in open bleeding. Antifibrinolytics given by mouth or injection are not used when there is blood in the urine.

WHAT ADVICE IS BEING GIVEN ABOUT THE TREATMENT OF CHILDREN?

Children with severe haemophilia must continue to receive treatment with blood products if they bleed. Failure to treat will result in an inevitable deterioration in health, and increase the likelihood of severe arthritis in young adult life.

In order to reduce the small risk of AIDS the present recommendation in Britain is that children under the age of 4 years should be treated with cryoprecipitate or small pool concentrate from carefully screened donors rather than with multi donor factor VIII concentrate, and with fresh frozen plasma rather than with factor IX concentrate. This recommendation might not be possible in the event of severe bleeding or the need for major surgery, or if a high level of clotting factor antibody is present. Older children who are severely affected should receive concentrates which have been heat treated.

Children without severe haemophilia may respond well to treatment other than blood products (see page 42).

WHAT SHOULD I TELL MY CHILDREN?

- Depending on age, that
- 'AIDS is like hepatitis and we have coped with that.'
- 'Like hepatitis, doctors are working on a vaccine to protect people.'
- 'Treatment is already being made safer by heating it, and I expect there will be other ways to make it better soon.'
- 'It isn't catching to other people like a cold.'

Questions raised by television or at school should be answered in a straight-forward, factual way. Reassure brothers and sisters.

SHOULD MY FAMILY DONATE BLOOD?

We have suggested that for the moment the immediate household members of at-risk patients should refrain from blood donation. Everything possible must be done to protect the recipients of blood product transfusion.

As with organ donation (page 46) these recommendations will almost certainly be changed once specific testing for AIDS is possible. This will be a most welcome advance as relatives of haemophiliacs are often highly motivated and generous donors.

Further advice on blood donation will be found on pages 58-59.

SHOULD I CARRY AN ORGAN DONOR CARD?

For the moment anyone who has received blood products prepared from the donations of several donors within the past 6 years should act his organ donor card aside. It is probably wise for his sexual partners to do the same. When more specific tests for AIDS become available these recommendations can be reviewed.

WHAT SHOULD I TELL MY NEIGHBOURS AND FRIENDS?

- The truth.
- Make sure they realise AIDS is **NOT** spread like 'flu' or measles.
- Explain that it has been a very rare complication of the use of concentrates and an even rarer complication of blood transfusion.
- Make sure they do not think that being at risk from AIDS, being investigated for AIDS, or having AIDS puts any sexual contactation on you or your family — because some haemophiliacs have contracted AIDS does not mean they were homosexual!
- Of course, the proportion of haemophiliacs who are homosexual is probably the same as in society at large.

**HOW LONG WILL IT BE BEFORE WE CAN
USE FACTOR VIII OR IX
MADE BY GENETIC ENGINEERING?**

Probably at least 5 years. Genetically engineered factor VIII has been made and shown to be effective in a dog with hemophilia. The major task now is to translate this great laboratory success into large scale production. Carefully monitored clinical trials will then be needed to ensure both the efficacy and the safety of the product before it goes into general use.

**GENERAL
ADVICE**

**CAN AIDS BE SPREAD BY
ORDINARY SOCIAL CONTACT?**

No.

Ordinary social contacts are perfectly safe. AIDS is only spread by close intimate contact or very rarely by blood transfusion. It is **not** spread in the ordinary activities of school, employment, pubs, public transport or places of entertainment. It is **not** spread by using the same toilet as somebody who might be at risk.

SHOULD I MAKE ANY CHANGES IN MY PERSONAL HYGIENE?

People in the high risk groups certainly should make changes. They are a matter of common sense. Those which relate to sex are discussed on page 39.

Because the virus is blood-borne, all cuts and abrasions, no matter how trivial, should be cleansed with an antiseptic and covered with a waterproof dressing until healed. Scabs should not be picked, nor should noses liable to bleeding! Disposal of disposable dressings, disposable tampons and sanitary towels etc., should be via a flushing lavatory, or sealed in a plastic bag for incineration. People on home therapy should check with their doctors about the correct procedures for the disposal of their used equipment (page 34).

If blood or blood product is spilt the surface should be cleaned immediately with household bleach — this destroys the virus (see page 21). Gloves should be worn by anyone (other than the patient) cleaning up spilt blood or equipment used for intravenous injection. This is especially important if the person concerned has any cuts or abrasions of the hands. A disposable plastic apron should be worn by anyone giving blood products.

Your dentist should be told if you are at risk. Special attention should be paid to dental hygiene. Toothbrushes and other dental appliances should be kept separately and never lent or borrowed; the same applies to nail brushes and to razors and blades. Every effort should be made to avoid gum disease (gingivitis), which results in bleeding; the advice of a dentist or dental hygienist should be sought early. Toothpicks, interdental sticks and floss used by at-risk people should be disposed of carefully by burning, or by sealing in a plastic bag for return to the hospital.

Advice on what to do with soiled clothing is given on page 20.

CAN AIDS BE SPREAD BY KISSING?

If it can this sort of spread is very rare. We are able to say this because of the absence of cases of AIDS that could only have been caused by kissing.

We do know that the AIDS virus is present in saliva, and so spread by kissing is theoretically possible, but only if infected saliva gains access to the bloodstream of the person being kissed. This means that it is safe for someone with haemophilia to kiss his children, as well as his partner.

The phlegm of some people with AIDS contains the virus. The same comments apply to this finding as to those given above on saliva. People in the at risk groups who get coughs and colds or bronchitis should use paper handkerchiefs, and dispose of them carefully.

ARE THERE ANY SPORTS OR ACTIVITIES THAT SOMEONE AT RISK SHOULD AVOID?

All the evidence points to a need for intimate contact for viral transfer and there is no reason for people with haemophilia, or indeed other blood recipients, to curtail their hobbies or sporting activities.

Obviously, things like 'blood brotherhood' in which there is an exchange of blood between participants, should be avoided. Tattooing and ear-piercing are best avoided as well, especially when performed by amateurs using unhygienic equipment.

See also under personal hygiene (page 52) and sexual activities (pages 39 and 62-63).

WHAT ADVICE IS BEING GIVEN ABOUT HEPATITIS B VACCINATION?

Vaccination is recommended to anyone likely to be exposed to the hepatitis B (Australia antigen) virus. Early fears that the vaccine may have been contaminated with AIDS have proved groundless.

Stages in the manufacturing process of the vaccine have been shown to remove viruses. Follow up of people who have received the full course of three injections has shown no cases of AIDS caused by the vaccine.

[Handwritten mark]

HOW SAFE IS AN ORDINARY BLOOD TRANSFUSION?

Very safe.

The chance of contracting AIDS from a transfusion of whole blood or any of its fresh or fresh frozen components is extremely remote.

Fact is that in the United States where 10,000,000 units of blood are given each year (1) have evidence of only 112 transfusion related patients in their 5 year follow up of all AIDS cases.

Very rarely an infected donor has evaded the surveillance of the blood transfusion services, and caused disease in a few recipients. This is what happened in Australia, and more recently some recipients of blood in the United Kingdom have become HIV III antibody positive.

Increased knowledge and responsibility among the donor population, better surveillance in both commercial and voluntary transfusion services, and the promise of specific tests for infectivity will reduce risk still further.

IS ARTIFICIAL BLOOD BEING DEVELOPED?

The name 'artificial blood' is misleading. There is a group of chemicals, called the perfluorocarbons, which are able to transport a small amount of oxygen round the body. They are being developed in Japan in the hope that they may be useful in situations where red cells are not available, for instance in wars or disasters. Apart from this, and sterile water containing salts and sugars which can be used instead of plasma proteins (albumin) in some cases, no substitutes exist.

IS BLOOD STILL NEEDED?

Certainly. Some of the most vital constituents of blood cannot be stored for long. Platelets can be used only within 3 days of donation. Red cells last only 5 weeks. Because of this donors are always needed just to cope with everyday demand.

Plasma constituents, like factor VIII, can be kept for longer. However, the ingredients from many donations are needed for treatment.

Please encourage people to become blood donors. They should read the warnings on page 59. Advice and details of donation may be obtained from the Blood Transfusion Services; details are given on pages 73-75.

IT IS NOT POSSIBLE TO CONTRACT AIDS BY DONATING BLOOD

WHO SHOULD NOT GIVE BLOOD OR PLASMA?

PEOPLE ARE ASKED NOT TO DONATE BLOOD OR PLASMA IF THEY ARE IN ANY OF THE FOLLOWING GROUPS:

1. Men who have had any homosexual contact in the past six years.
2. Bisexual men (as above) and their heterosexual partners.
3. Sexual contacts of people receiving multiple blood transfusions, including haemophiliacs.
4. Sexual contacts of people with AIDS.
5. Present or former drug addicts who have injected themselves in the past six years, and their heterosexual partners.
6. People who have arrived or returned from Zaire or surrounding countries in East and Central Africa, or from Haiti in the last few years, and their sexual partners.

In addition, it is now staff policy in our Centre to refrain from donating blood.

CAN THE SOURCE OF A PATIENT'S AIDS BE IDENTIFIED?

Not always. It really depends on his or her lifestyle, and on the type of blood product used for treatment.

In the absence of a specific test for AIDS even seemingly obvious links are often in doubt. However, when more than one person develops AIDS following transfusion of blood collected from the same donor, who also develops AIDS, a connection is established. Similarly a connection can be inferred when someone who has been shown to be HTLV III antibody negative becomes HTLV III positive after blood product transfusion; this is called 'seroconversion'. Seroconversions like this in the absence of other risk factors are powerful indicators of exposure to the AIDS virus.

The tracing of infection becomes almost impossible when blood products prepared from multiple donations have been used. This is the case in most haemophilias, because many factor VIII and IX concentrates are manufactured from huge numbers of plasma donations, often from as many as 30,000 donors.

It is not usually possible to show that transfusion of any one batch of pooled blood product resulted in infection because:

- not everyone exposed to it becomes HTLV III antibody positive or develops AIDS
- the incubation period is so long, and variable
- most severely affected haemophilias have used many different batches over the years
- so many batches seem to have been infected over a long period.

IF I GET AIDS FROM BLOOD TRANSFUSION CAN I OR MY FAMILY SUE FOR DAMAGES?

Of course. Legal action has already been started against at least one commercial blood product company in the United States.

However, in order for the action to be successful it is probable that the court would have to be convinced of at least the following points:

1. That the transfusion itself was the cause.
2. That in deciding to advise the transfusion the doctor acted negligently.
3. That the doctor did not ensure up to a reasonable standard that the transfusion was safe; and/or
4. That the manufacturer had not taken reasonable precautions to ensure that the product supplied to the doctor was safe.

Because it is not yet possible to test all blood products for AIDS it might be difficult to establish the causal link. Other known causes would have to be excluded as well.

Negligence could only be established either against the doctor or manufacturer with detailed and expert knowledge of the circumstances. Transfusion is never prescribed without careful thought not just because of AIDS but because of the chance of other hazards especially the possibility of hepatitis. In deciding whether negligence had occurred a Court would apply the standard of a 'reasonably competent doctor' or a 'reasonably competent manufacturer' — i.e. a standard of care would be required consistent with accepted good clinical practice.

Often, the decision to transfuse has to be taken as one of a series of decisions, the final outcome of which should of course help rather than hinder a patient's recovery. The withholding of transfusion because of the remote risk of AIDS from someone with multiple injuries after a crash, or from a mother who has haemorrhaged after childbirth, could not be justified. Nor could failure to treat the underlying cause of severe haemophilic-bleeding, the deficiency in clotting factor. Other ways of dealing with less complex problems may carry significant side effects themselves, and these too must be considered and weighed against the risk of AIDS by the doctor responsible for making the decision.

WHAT ADVICE IS BEING GIVEN TO HOMOSEXUALS?

The Terrence Higgins Trust has published advice for gay men. Their leaflet, which is updated as knowledge grows, may be obtained with additional information from the address given on page 71. It reads as follows:

HOW CAN YOU REDUCE YOUR RISK OF GETTING AIDS?

1. Have sex with fewer men.
2. Avoid anal sex, except possibly with your regular partner(s).
3. Have sex only with men whom you know to be in good health and who have had few other sexual partners.
4. Avoid sex with men who have been sexually active in North America in the last three years.
5. Since the virus has been found even in saliva, perhaps the only safe sex is mutual masturbation, body rubbing, and dry kissing.

Until we know more you should **NOT** give blood or carry an organ donor card.

IS THERE A TEST FOR AIDS?

No. Researchers are now using a test (the HTLV III antibody test) which shows whether a person has been infected with HTLV III (the probable AIDS virus) at some time.

It does not show:

1. Whether infection is still present.
2. Whether any illness will develop.
3. Whether the infection can be passed on.

It is therefore **not** a test for AIDS.

WHAT SHOULD YOU DO IF YOU ARE TOLD YOU ARE HTLV III ANTIBODY TEST POSITIVE?

1. Don't panic — most people stay well.
2. Have sex only with your regular partner(s).
3. Talk again with the doctor who told you the result if you are unclear about anything.
4. The Terrence Higgins Trust exists to give you help and advice.

WHAT SHOULD YOU DO IF YOU HAVE HAD SEX WITH SOMEONE WHO DEVELOPS AIDS (OR HAS PERSISTENT GENERALISED LYMPHADENOPATHY OR IS HTLV III ANTIBODY POSITIVE)?

Again, don't panic. Your risk of illness is small. Consult a doctor at a Sexually Transmitted Diseases (VD) Clinic.

WHY DO ONLY SOME PEOPLE INFECTED WITH THE VIRUS GET AIDS?

We do not know for certain, but we have some ideas.

1. Some people are born better able to fight this infection.
2. Other infections (syphilis, hepatitis, glandular fever, CMV* etc.) may make the AIDS virus more active in the body.
3. Many recreational drugs may reduce the body's ability to fight infection (this applies even to the heavy use of tobacco and alcohol).
4. Receiving other men's semen into your body may also reduce the body's ability to fight infection.

DO CONDOMS REDUCE THE RISK OF INFECTION WITH THE AIDS VIRUS?

We do not know. Anal sex carries a high risk of transmitting the virus. We worry that as condoms may easily tear or come off during anal sex they will not provide adequate protection. We recommend that you avoid anal sex except possibly with your regular partner(s). If you decide not to follow this advice condoms may offer some worthwhile protection.

* cytomegalovirus

IS THERE ANYTHING I CAN DO TO HELP OTHERS?

Yes.

There are two urgent needs:

- finance for research and the development of facilities, and
- dissemination of fact rather than fiction about AIDS. People should have easy access to expert counselling.

In addition everything possible needs to be done to encourage the growth of independent, well-funded blood transfusion services based on the unpaid, volunteer donor system.

The saying 'A problem shared is a problem halved' is very true in the context of a threat like AIDS. Share your thoughts and worries with other people in the relevant societies and groups. Some useful addresses are given on page 71.

Never be frightened of going to talk to your doctor and of encouraging others, who may be worried to do so. If the doctor cannot answer your questions he will be able to suggest referral to someone who can.

APPENDIX

Appendix.

THE BODY'S DEFENCE CELLS

Within the blood are three types of cell. Red cells transport oxygen, platelets help control bleeding, and white cells protect the body against harm from infections and other invaders.

White cells and immunity

There are several different types of white cell, each with a specific task in helping to protect the body. There are around 5000 of them in a millilitre of blood. In adults the commonest white cell, or leukocyte (leuko = white, cyte = cell) is the granulocyte, so called because of the granules it contains. Granulocytes are like amoebae, the tiny single celled organisms studied under the microscope by school children. As well as being carried round the body passively in the blood stream, granulocytes are able to attach to and creep along surfaces by extending pseudopodia (false feet). Their ability to do this and to change their shape allows them to find their way through the walls of blood vessels and into the tissues. Here they scavenge foreign and waste materials. These refuse collectors of the body are stimulated especially when a bacterial attack is mounted. As bacteria invade they become coated with antibodies which are recognised by the granulocytes. Using a combination of chemical warfare and an ability literally to eat their opponents the granulocytes fight the infection, many dying in the process. Masses of dead granulocytes form pus.

The other main type of white cell, commonest in children, is called the lymphocyte. Recent work has revealed a host of new information about how lymphocytes work, information which is at the core of our understanding about how the body responds to substances foreign to it, including transplants and cancers.

Lymph

In addition to the circulatory system, which carries the blood around the body, there is another system which carries a fluid called lymph. Lymph, which comes through vessel walls from the blood, is collected from the tissues, filtered through structures called lymph nodes, and returned to the blood stream. Lymph nodes are known to most people as 'glands'. Although sited throughout the body, they may be felt with especial ease at the sides of the neck, in the armpits, in the groins. If an infection, for instance a boil, occurs in the territory of a set of lymph nodes they become enlarged as their cells respond to the bacteria and may become sore. The enlargement is called lymphadenopathy.

The lymph nodes contain nests of cells programmed to combat invasion. There are two sorts of lymphocytes and they are called T and B cells. B cells are lymphocytes that are programmed by the bone marrow, and other tissues. When they come into contact with antigens (recognition sites on bacterial invaders) B lymphocytes develop into another form called plasma cells, and plasma cells produce a very potent defensive weapon called antibody or immunoglobulin. The immunoglobulins protect the body from mass bacterial invasion and some viral infections, and are responsible for preventing second infections against viruses, and toxins produced during bacterial warfare.

T cells are cells that have received their instructions on what to fight in an organ called the thymus, which lies just behind the top of the bronchus. The thymus is big in small children, and there are many lymphocytes, because there is a lot to learn about how to spot an invader. T cells are involved principally in the recognition of infections within cells, for instance, first virus infections and some fungi and parasites. T cells protect either by destroying infected cells or by walling off infected areas with the help of other white cells. They are primed to recognise minor changes in the tissue and it is the very effectiveness of this recognition that makes them responsible for the rejection of kidney and skin grafts from unrelated individuals.

The complex workings of T and B cells, and of the defence system of which they are a part, are termed collectively the immune system, and the science of their study is immunology (immunis is the Latin word for 'exempt' or 'secure').

It is obvious that everyday life produces multiple challenges to our immune system, and that sometimes, perhaps whilst it learns about a previously unknown invader, it appears to fail us. It is when its failure is prolonged that real problems can arise. Such a situation may be produced on purpose with drugs in order to trick the body into accepting a transplant, or rejecting a cancer. However, it may also occur as the result of overwhelming invasion or continued bombardment by the invading forces, and there are also relatively rare inherited disorders of immunodeficiency. In some of these cases both T and B cells are affected with dire consequences if the condition is not spotted early enough. More commonly a deficiency only affects one arm, or part of one arm, of the immune system. The acquired immunodeficiency syndrome is an example of a failure in T cell function. Because B cells are not affected, bacterial infections in AIDS are extremely rare, but patients suffer from infection with viruses, fungi like candida ('thrush'), and other invaders which are usually held at bay by the T cell system.

INFORMATION

**USEFUL ADDRESSES AND
TELEPHONE NUMBERS**

World Hemophilia AIDS Center (WHAC)
2400 South Flower Street
Los Angeles
California 90007
USA

Tel: (213) 742-1354 Telex: 6502283270 MCI

UK Haemophilia Society
PO Box 9
16 Trinity Street
London SE1 1DE
England
Tel: (01) 407 1010

USA National Hemophilia Foundation
19 West 34th Street
Suite 1204
New York NY 10001
USA
Tel: (212) 563-0211

World Federation of Hemophilia
Suite 1517
1155 Dorchester Boulevard West
Montreal
Quebec H3B 2J6
Canada
Tel: (514) 866-0442

Terrence Higgins Trust
BM AIDS
London WC1N 3XX
Tel: (01) 278 8745

London Gay Switchboard
Tel: (01) 837 7324

UK HAEMOPHILIA REFERENCE CENTRES

- Haemophilia Centre,
Coagulation Laboratory
Department of Haematology
St Thomas' Hospital
London SE1 7EH
Tel: 01 928 9292 Ext. 2268
- The Katherine Dormandy Haemophilia Centre and Haematology Unit
Royal Free Hospital
Pond Street
London NW3 2QG
Tel: 01 794 0500 Ext. 3807
- Oxford Haemophilia Centre
Churchill Hospital
Headington
Oxford OX3 7LJ
Tel: 0865 64841 Ext. 532
- Department of Clinical Haematology
The Royal Infirmary
Manchester M13 9WL,
Ward P2
Tel: 061 273 3300 Ext. 237
- Royal Hallamshire Hospital
Glossop Road
Sheffield S10 2JF
Tel: 0742 26484 Ext. 2377
- Cardiff Haemophilia Centre
University Hospital of Wales
Heath Park
Cardiff CF4 4XN
Tel: 0222 755944 Ext. 2155
- Department of Haematology
Royal Victoria Hospital
Grosvenor Road
Belfast BT12 6BA
Tel: 0232 40503
- Department of Haematology
Royal Infirmary
Lauriston Place
Edinburgh
Tel: 031 229 2477 Ext. 2099
- Regional Haemophilia Centre
Department of Medicine
Royal Infirmary
Glasgow G4 0SF
Tel: 041 552 3535 Ext. 5127
- Haemophilia Centre
The Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne NE1 4LP
Tel: 0632 325131 Ext. 773

REGIONAL CENTRES OF THE NATIONAL BLOOD TRANSFUSION SERVICE IN THE UK

ENGLAND

NORTHERN REGION

Regional Transfusion Centre
Westgate Road
Newcastle upon Tyne NE4 6QR
Tel: 0632 737804/8

YORKSHIRE REGION

Regional Transfusion Centre
Bridle Path
Leeds LS15 7TW
Tel: 0532 645091/3

TRENT REGION

Regional Transfusion Centre
Longley Lane
Sheffield S5 7JN
Tel: 0742 387201

EAST ANGLIAN REGION

Regional Transfusion and
Immuno-haematology Centre
Long Road
Cambridge CB2 2PT
Tel: 0223 245921

NORTH WEST THAMES REGION

North London Blood Transfusion Centre
Deansbrook Road
Edgware
Middlesex HA8 9BD
Tel: 01 952 5511

NORTH EAST THAMES

North East Thames Regional Transfusion
Centre
Crescent Drive
Brentwood
Essex CM15 8DP
Tel: 0277 223545

SOUTH EAST AND SOUTH WEST THAMES REGIONS

South London Transfusion Centre
75 Cranmer Terrace
London SW17 0RB
Tel: 01 672 8501/7

South London Transfusion Sub-Centre
David Salomon's House
Southborough
Nr. Tonbridge
Kent
Tel: 0892 28172

WESSEX REGION

Wessex Regional Transfusion Centre
Coxford Road
Southampton SO9 5UP
Tel: 0703 776441

OXFORD REGION

Regional Transfusion Centre
John Radcliffe Hospital
Headington
Oxford OX3 7LJ
Tel: 0865 65711

SOUTH WESTERN REGION

South West Regional Transfusion Centre
Southmead Road
Bristol BS10 5ND
Tel: 0272 507777

WEST MIDLANDS REGION

Regional Transfusion Centre
Vincent Drive
Edgbaston
Birmingham B15 2SG
Tel: 021 472 3111

MERSEY REGION

Regional Blood Transfusion Centre
West Derby Street
Mount Vernon
Liverpool L7 8FW
Tel: 051 709 7272

NORTH WESTERN REGION

Regional Transfusion Centre
Plymouth Grove
Manchester M13 9JL
Tel: 061 273 7181

Transfusion Centre
Quernmore Road
Lancaster LA1 3JP
Tel: 0524 63456

WALES

Regional Transfusion Centre
Rhyd-Lafar
St Fagans
Cardiff CF5 6XF
Tel: 0222 890302

SCOTLAND

North of Scotland Blood Transfusion Service
Raigmore Hospital
Inverness IV2 3UJ
Tel: 0463 34151

SCOTLAND (cont'd)

Aberdeen and North-East Scotland Blood Transfusion Service
Royal Infirmary
Foresterhill
Aberdeen AB9 2ZW
Tel: 0224 681818 Ext. 2086

East of Scotland Blood Transfusion Service
Ninewells Hospital
Dundee DD1 9SY
Tel: 0382 645166

Edinburgh and South-East Scotland Blood Transfusion Service
Royal Infirmary
Edinburgh EH3 9HB
Tel: 031 229 2585

Glasgow and West of Scotland Blood Transfusion Service
Law Hospital
Carluke
Lanarkshire ML8 5ES
Tel: 0698 373315

Scottish National Blood Transfusion Service
Headquarters Office
Ellen's Glen Road
Edinburgh EH17 7QT
Tel: 031 664 2317

NORTHERN IRELAND

Blood Transfusion Service
89 Durham Street
Belfast BT12 4GE
Tel: 0232 46464

FURTHER INFORMATION

'Some facts about AIDS', published 1985 by the Health Education Council, 78 New Oxford Street, London WC1A 1AH. Free

'AIDS and how it concerns blood donors', published 1983 by the National Blood Transfusion Service. Update in press: 'AIDS - important new advice for blood donors', prepared by DHSS and Central Office of Information for the National Blood Transfusion Service. Free.

A leaflet is also available from the Scottish National Blood Transfusion Service. Free.

'AIDS: the facts', published 1984 by the Terrence Higgins Trust, BM/AIDS, London WC1N 3XX. Free

'HAEMOPHILIA', regularly updated leaflets published by the Haemophilia Society, PO Box 9, 16 Trinity Street, London SE1 1DE. Free.

Fisher R B 'AIDS: your questions answered', published 1984 by Gay Men's Press, London ISBN 0-907040-29-2 £1.95

Mayer K and Pizer H 'The AIDS fact book', published 1983 by Bantam Books, New York ISBN 0-553-23870-1 £1.95

DETAILED GUIDELINES FOR HEALTH WORKERS

'AIDS - Interim Guidelines', published 1984 by the Advisory Committee on Dangerous Pathogens on behalf of the Health and Safety Executive and the Department of Health and Social Security together with Health Circular HC(85)1 which has been sent to Community Health Councils for information.

'AIDS: Nursing Guidelines', published 1985 by the Royal College of Nursing, London. £3.75

CALL FOR COMMENT

Given the demand, it is intended to publish new editions of this booklet at intervals in order to report advances in our knowledge of AIDS and the blood.

Comments, corrections and questions for publication are most welcome. Would readers please send them to me at the address below. In order to save time and money receipt of comments will not be acknowledged unless a specific request is made to the contrary.

Thank you for your help.

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