

ADVICE SHEET FOR ADULT PATIENTS AND FAMILIESACQUIRED IMMUNE DEFICIENCY (AIDS)

We hope you will find this fact-sheet useful and that the information in it will complement that given by your Haemophilia Centre Director. It is important that you understand a little about this very new disease and its implications for people with haemophilia. As you will appreciate, the pace of research is moving very fast and we will be in touch with you and your family as further information becomes available. If however, you have any major anxieties in the meantime please do not hesitate to phone your Centre Director for a personal appointment (Glasgow 041-552-3535 Ext. 5127; Edinburgh 031-229-2477 Ext. 2099).

1. What is AIDS?

This is a new disease, probably due to a virus which harms the immune system of the person affected. The result is that they have a reduced ability to combat infections.

2. Where did it come from?

The evidence suggests that the original virus has come from Africa (Zaire or Chad) and been transported to Haiti and then to the USA. In haemophilia, the evidence is that it has been transmitted by blood products and is now therefore present in most countries of the world. It is still however an extremely rare disorder - and has affected only 3 haemophilic patients in the U.K.

3. Who does it affect?

The majority of people affected are homosexuals or their male (and female) partners. There is clear evidence of sexual transmission in this group and the virus has been found in semen. In addition some females with many sexual partners have acquired the infection sexually. Intravenous drug abusers, haemophiliacs and blood transfusion patients are probably infected by blood borne transmission. In this way transmission of the disease resembles hepatitis B.

4. Why does immunity alter?

Our immune system, which fights infection, is extremely complex and involves certain cells and antibodies in our blood. The virus attacks one cell type (lymphocytes) which play a key role in the body's defences. Some of these cells are called helper or T₄ cells. It is likely that, at routine visits patients will have the numbers of these cells counted. It is only if there is a major destruction of these cells that immunity is significantly reduced.

5. How does AIDS affect patients?

As immunity is suppressed, the patient becomes liable to infections of all kinds especially to bacterial infections which previously were not powerful enough to penetrate the body's defences. Pneumonia is also common, but this, of course, can be treated. Fungal infection such as thrush may occur, and we normally live happily with these organisms in our bodies which only get out of control with loss of immunity. Again effective anti-fungal agents are available. Other viruses may also appear, e.g. herpes simplex ("cold sore" virus). This will spread locally as the body cannot mount its normal immune defence. Anti-viral agents are now in use and new and more effective ones are being developed.

6. What is the virus?

The virus probably responsible is called Human T-cell Lymphotropic Virus (HTLV III). Its main action is to reduce the effectiveness of a particular cell (T₄ cells) in the immune process. Exposure to the virus results in the body making an antibody (HTLV III Ab) to the virus protein and this is now used as a marker of exposure to the virus. These tests are now available and will be carried out on your routine visits to your centre. About half the patients in England and about ten per cent in Scotland have had exposure and are HTLV III Ab-positive.

7. What are the implications?

The implications of a positive HTLV-III Ab test are not known. All we can say for certain is that the positive test means that the person has been exposed to the virus proteins. It would seem reasonable now for all patients who have had concentrates, no matter from which source, to take simple measures to limit the possible spread of infection. These should include -

(a) You should make up and handle your own bottles of concentrate. Great care must be taken not to contaminate work surfaces with spilled concentrate. Care must be taken with used needles and syringes and these must be returned (in "Cinbins") for disposal in the Centre. Any spillage of material should be washed up with a solution of a household disinfectant. Hands should be washed in ordinary soap and water and garments splashed with concentrate should be washed as normal in your washing machine with a hot rinse. After use the work surface should be washed with a household disinfectant such as Milton. It is better not to use a place on which food is prepared.

(b) If anyone in the family wishes to help prepare concentrates and injections they should wear gloves and disposable plastic aprons (provided). Both these measures (a) and (b) should be used routinely.

(c) As sexual intercourse has been shown to be involved in the spread of the disease the wearing of a condom (sheath) during intercourse. You should abstain from rectal or oral sex. Also if you wish to consider having a baby you should discuss this with your haemophilia Director in advance.

(d) All relatives living in the same house with the family should refrain from giving blood. This is a simple precaution only.

(e) The problem of dental care will also have to be organised and further advice will be given about this.

It is to be EMPHASISED that these are only simple precautions for you and your family. No changes need occur in your day-to-day life with friends, neighbours, at school or at work.

8. So what is being done?!

As of now, all factor VIII concentrate is being heat-treated to destroy the virus. You will be given heat treated factor VIII as soon as possible.

In addition, the Transfusion Service is making every effort to ensure people who have a greater than average risk of exposure to AIDS do not donate and all donors are required to sign that they are not in a high risk group. Also we hope that in the near future it will be possible to test all blood donations for the presence of HTLV III antibody. These measures will effectively remove sources of virus from the donor pool.

In the next few years we hope to have available a new preparation of factor VIII which is made by genetic engineering. This will not involve blood products and therefore cannot be a source of infection. Already test batches are being prepared so it is only a matter of time and we predict that supplies will be available in the next four years.

9. Reassurance

We realise how worried some of you may be and this is the reason that we have called a series of meetings of patients and relatives. We will keep you informed of all new developments. If anyone wishes a further discussion please phone your Centre Director for a private chat. Bring your spouse if you wish.

Remember that you must continue to treat yourself with the concentrates as the risks are much greater of bleeding than of contracting the rare disease of AIDS.