

IN CONFIDENCE

EXPERT ADVISORY GROUP ON AIDS

CONFIDENTIALITY OF INFORMATION RELATING TO ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

The attached paper was considered by the Ministerial Steering Group on AIDS at its meeting on 15 April. Subject to the EAGA's consideration of the medical content of the paper, the Steering Group,

- a. endorsed the general principle of confidentiality proposed in the paper;
- b. invited Departments to be guided by that principle; and
- c. endorsed the proposal for the preparation of model counselling guidance.

The views of EAGA members on the medical content of the paper would be welcomed.

15/4/86

Confidentiality of Information relating to Acquired Immune Deficiency Syndrome

Summary

This paper seeks to formulate a general principle to guide those who must handle the information that an individual is infected with the HTLVIII virus (the AIDS virus). Having regard to:

- the modes of transmission of the virus;
- the efficacy of standard hygienic practices against it;
- the importance of retaining the co-operation of infected persons; and
- the ethical codes of the health professions;

it is proposed as a general rule that information identifying an infected person should not be passed to any other person without the consent of the infected individual.

The problem

2. Public pressure to know whether a person is infected arises naturally from the fear of transmission of infection and the desire to know whether they need to take action to avoid the risk. The facts on transmission are not well understood by the public, and the current health education campaign is designed to produce authoritative statements to reduce misunderstanding and unnecessary fears. The virus is transmitted primarily through sexual intercourse, mainly but not exclusively between homosexuals, or by drug abusers sharing their equipment. It is not transmitted by normal social contact, nor for example by working with an infected person or being at school with them. Hence the risk of transmission in normal circumstances at work or school or in the home is very small indeed and can be reduced if, when accidents happen, sensible hygienic practice is followed.
3. In general the more disclosure there is of the identity of infected persons, the less likely it is that people will come forward for testing. The public education campaign should help to reduce unwarranted demands for identification. However, questions about who should know when a person is infected will still arise in a wide range of situations, for example a wife concerning her husband; an employer in relation to employees; a head teacher in relation to schoolchildren; the director of an

Infected persons

8. The overriding need not to discourage persons from seeking medical advice and testing together with the unlikelihood that informing anyone other than his personal physician will serve the interests of an infected person, argue against introducing any general requirement on individuals to disclose the information about their infection to others.

9. As regards employment, S7 of the Health and Safety at Work Act places an employee under a general obligation to co-operate with his employers on safety matters and to take reasonable care of the health and safety of himself and others. There may, exceptionally, be circumstances where an infected employee already has a responsibility - and possibly a duty under the Act - to disclose his infection to his employer. Subject to that, the general guidance should be that employees should not need to inform their employers if they are infected and should not be encouraged to do so.

10. It is expected that an infected person's doctor (or other counsellor) would counsel them strongly to disclose his/her condition, or agree to disclosure, to sexual partners (and especially in the case of wives/husbands). Where this advice was rejected, the decision would be for the individual doctor to take the light of his judgment of the ethical and medical considerations and the balance of risk to the health of others.

11. Where a child is infected, doctors would normally inform the parents. For older children, doctors can be expected to act in accordance with the ethical considerations applying generally when questions arise over informing the parents about the health of their child. Special considerations arise where the child has been taken into care by a local authority. These will require further examination.

12. The risks of transmission of infection at school (whether day or boarding) are not generally such as to warrant any specific requirement on parents to inform the school authorities/headmaster of infected children. There could, exceptionally, be circumstances eg with an aggressive or handicapped child, children involved in drug misuse or homosexuality, where a parent might be counselled by his doctor to do so. In the event that the advice was rejected, it would be open to the doctor to inform the authorities, subject to consideration of his ethical obligations, and to inform parents accordingly.

17. To support the general approach outlined above, it is proposed that the Health Departments should produce model counselling guidance that could be used in helping infected people. It will include reference to social, educational, and employment issues including the provisions of the Health and Safety at Work Act.

18. Risk of infection is higher where the use of invasive clinical techniques and the handling of infected body fluids are involved. as in the health care environment. ~~It has been agreed~~

that all health care staff should be informed, in advance if possible, of patients who will be under their care or of material they may be asked to handle which could present a risk of infection. However, staff undertaking invasive procedures need to know the precise nature of the risks for example, when it is known that a patient is HTLVIII antibody positive. As regards health care staff who are infected, guidance is being prepared concerning the precautions an infected person should take and specialised types of work to avoid. No need is seen for any derogation from the general rule that infected employees need not inform their employer.

Conclusion

19. Ministers are invited to:

- a. endorse the general principle of confidentiality proposed in paragraph 15;
- b. agree that this approach should be used as far as possible in preparing public guidance to be issued by Departments; and
- c. endorse the proposal in paragraph 17 for model counselling guidance.