AIDS AND HAEMOPHILIA
The Hidden Disaster

11 — The Home Nurse

Haemophilia, for the layman, is a medical enigma. It is one of those disorders that people have heard of but know little about. There have always been fears of the person with haemophilia that if cuts himself, that he will simply bleed to death. Of course, haemophilia also has its romantic side. After all the Tsarevich's haemophilia was responsible for Rasputin's omnipotent position within the Russian Court prior to the Revolution. Queen Victoria was also a carrier. On one level haemophilia might be the stuff of which epic dramas are made. Yet, at the same time it is also an everyday concern for over five thousand men in the U.K.

Haemophilia is an hereditary disorder passed only from mothers to their sons. Despite popular belief, you do not bleed to death from the smallest cut. However, haemophilia is a life threatening disorder. Bleeds into joints and muscles causes acute pain and, due to the bloods toxicity to bone, severe arthritis. The most common form of death for people with haemophilia, after suicide, is cerebral haemorrhages. The reason for this internal bleeding is that the blood of the majority of people with haemophilia is missing the clotting factor VIII. The prognosis of haemophilia for centuries had been disablement, early death and isolation. However, from the 1950's onwards a revolution took place in haemophilia care.

In 1950 the Haemophilia Society was established. The Society has numerous functions. It exists in a pastoral capacity acting as a central body with local groups which provide various services from answering questions on haemophilia to offering Society caravans for U.K. holidays. It also assists in obtaining Mobility and Attendance Allowance and advises on other welfare benefits and rights. The Society is also able to offer grants for certain welfare problems. An additional function of the Society is to promote research into and study the causes, diagnosis and treatment of haemophilia.

The primary cause for this revolution in haemophilia care was the introduction of factor VIII concentrate. Individuals after 1974 were encouraged to inject themselves at home with factor VIII when ever they felt a bleed commence. Alternatively in severe cases, home treatment was used as a prophylactic to prevent bleeds starting. The results of

this new found independence for people with haemophilia were startling. No longer were sufferers banished to bed or hospital at the onset of a bleed. For those young enough to be treated with factor VIII from birth the threat of arthritis was diminished. People with haemophilia were therefore given access to accepted life patterns. They no longer demanded special consideration on account of their haemophilia and could attend schools, universities and places of work without worrying about excess absence due to ill health.

The infection of blood products by the Human Immunodeficiency Virus (HIV) has reversed these developments. Twelve hundred people with haemophilia and HIV once again face disablement, early death and isolation. Ironically they may have won the battle against living with their hereditary disorder, however, by doing so they have become iatrogenically infected by a virus whose implications are far more devastating. People with haemophilia and HIV are now instantly exempt from life insurance and mortgage endowment policies. They are once again set up, quite unjustifiably, as social outcasts. Their desirability as members of the community are again being questioned. On top of bearing this social burden HIV sufferers also have a medical condition which places a huge financial pressure upon domestic resources. The economic price of living with haemophilia has forced many to claim maximum DHSS benefits on account of their blood disorder alone. Many income brackets cannot afford the increased cost of HIV/AIDS.

The story of haemophilia and HIV is tragic. However, the Society and its members are no longer solely concerned with sympathy. The Society wants action. The Social Services Committee on problems associated with AIDS (1987) concluded that, "the needs of haemophiliacs deserved special consideration." People with haemophilia and HIV need help. The Government has suggested the Society go through the courts and seek legal redress. Whether negligence can be proved is a moot point. Yet, what is clear is that even if such legal action were successful any form of compensation would arrive too late for the litigants. At present sixty people with haemophilia and HIV have developed AIDS, forty five of whom have died. These figures have doubled since the spring. It is still impossible to state that all those who have HIV antibodies will go on to develop AIDS, however, the signs are ominous.

The tragedy of twelve hundred people dying as a result of National Health Service treatment is a disaster in its own right. The Social and financial implications surrounding their infection and possible death place that disaster upon epic proportions. The Government is the only institution capable of minimalising the distress of all those concerned. It is for that reason that the Society is petitioning the Government to provide an insurance scheme, a benefit for widows and other dependents upon the death of the husband or breadwinner and also a weekly benefit to help cope with living with AIDS. There is also a claim for a solatium to be provided to help redress the unquantifiable emotional anguish caused by HIV infection.

The needs of people with haemophilia and HIV are urgent. The Society does not want to do battle with the Government over responsibility for the quality of blood products. Alternatively, the Society pleads for the Government to show compassion and to act responsibly. Dr. Peter Jones's leader in the British Medical Journal (17 October 1987 Vol 295 page 944) indicated how the Government could implement action immediately. As he points out, the 1978 Royal Commission on Civil Liability and Compensation for Personal Injury (The Pearson Report) and the 1979 Vaccine Damage Payments Act could provide government with ways forward in dealing with this chronic situation.

Outside HIV infection the treatment of haemophilia continues to progress. The gene which causes the disorder has now been identified and developments are taking place to manufacture a synthetic product to replace human plasma based factor VIII. Treatment of haemophilia has therefore come a long way from the impotence which faced the Tsarevich upon each of his bleeds. Those suffering from haemophilia are no longer dependent upon the sorcery of Rasputin and the like. The revolution in treatment is secure, however, along the way of establishing that revolution twelve hundred people have been infected by a potentially debilitating and fatal disease. Some may argue that that is the price that has to be paid. However, what cannot be disputed is that these people deserve all the care and compassion our society has to offer. The Haemophilia Society therefore pleads that the Government stops prevaricating and acts swiftly to mitigate the distress of its members.

JONATHAN COOPER
Aids Co-ordinator

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