

The Haemophilia Society Draft Policy on Contaminated Blood

Introduction

In the 1970s and 1980s, a large proportion of blood products supplied to patients by the NHS were contaminated with HIV or Hepatitis C viruses: at least 1,757 patients with Haemophilia have subsequently died from the effects of these viruses of the over 4,670 exposed to infection.

The risk of viral contamination, particularly from blood sourced in the USA, became known in the 1970s, although the existence of HIV and the lethality of Hepatitis C were not established until the 1980s. In response to the known risk, the government in 1975 committed to the UK becoming self-sufficient in the main blood product used to treat Haemophilia (Factor VIII) 'within two to three years'. This promise was never kept. Heat treatment of blood products to destroy viruses finally became available in the early 1980s but was not fully implemented until 1986.

The NHS made no clear communication of the known risks to patients, and did not change practice to avoid use of blood products for patients who required treatment only infrequently and could have been adequately treated with safer alternatives.

Successive governments have refused to hold a Statutory Public Inquiry into these events. An independent Inquiry under Lord Archer opened in 2007 and reported in 2009: this followed the procedures of a Statutory Public Inquiry but had no power to compel anyone to give evidence or to produce documents. Lord Archer made strong recommendations to government, some but not all of which have been implemented.

Summary

This policy comprises three main demands: an acknowledgement by the Prime Minister, a Public Inquiry, and immediate interim steps to give equitable support to those affected.

This policy relates only to the Society's constituency of those with bleeding disorders. The Society recognises that people without bleeding disorders were also infected through whole blood transfusions, but it cannot express an opinion on the appropriate policy for this group.

The Society will review this policy after the Penrose Inquiry in Scotland reports in 2013.

Acknowledgement by the Prime Minister

The Society demands a public acknowledgement by the Government, given by the Prime Minister in a statement to Parliament, of the circumstances in the 1970s and 1980s which resulted in thousands of people being infected through contaminated blood. This should include recognition that mistakes were made by the Government of the time and by its Departments and Agencies, together with acceptance that this at the least creates the moral obligation on the Government to institute a payment and treatment regime for those affected which allows them to live in dignity and removes them from needing to rely on the benefits system or on a system of discretionary trusts. (They should of course still be able to access the benefits system if needed, as for the general population.)

Statutory Public Inquiry

The Society further demands a Statutory Public Inquiry into the circumstances which resulted in the contamination. The Inquiry terms of reference should include a focus on avoiding future medical disasters. Successive Governments have stated that they have learned and implemented all lessons from these events, but only a public review of the facts can prove this.

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The Government must not, however, use the creation of such an Inquiry as an excuse for delaying rectification of current inadequate support for those affected, as outlined below.

Equitable support

Those infected often have conditions which prevent them working and which generate specialised medical needs. Both the infected and their families can have deep rooted psychological problems from the continued trauma of the experience; again this can require specialised treatment. Some partners have been infected through sexual transmission, and this has also led to some children being born with the infection, and these have the same needs as those infected directly. Where family members have acted as carers for decades with minimum support, this generates additional stresses and needs.

Given the immediate financial, medical, psychological, and counselling needs of many of those infected plus their dependants and survivors, the Society urgently requests that, pending any proof of liability, Government implements an individual holistic needs-based and impact-based assessment for all those affected, with the goal of optimising clinical support, providing to the greatest extent possible for their emotional well being, and removing them from having to apply for further relief through the benefits system.

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We believe that it is practical and affordable to run such a system for the few thousand cases which exist. If the government queries the practicality of such individual assessment, we would suggest a trial to be run in a representative region of the country.

Pending the introduction of individual need-based and impact-based assessment the Society demands that the Government urgently rectifies gross inequities in the existing system, including:

- The process of applications by widows and dependants to the Skipton Fund, especially where medical records are missing. Where records are missing or inadequate, the “balance of probability” should be applied to make the assumption that an unexplained death of someone infected with Hepatitis C was caused by the virus’s action on the liver and therefore qualifies for “Stage 2” payments.
- Adequate payment for those with Hepatitis C not qualifying for “Skipton Stage 2”. Anecdote and emerging medical evidence suggest that those infected with Hepatitis C but with no visible damage to the liver can still have chronic symptoms affecting their ability to earn a living and their need for support. The Skipton evaluation and payment regime should reflect this need.
- Recognition that those contaminated in general cannot get life assurance at any practical price and either (i) implement a Government underwriting scheme to provide affordable assurance or (ii) provide continued payments to the dependants after death of the infected person as a substitute for assurance. The scheme implemented should also resolve the issue of mortgages below.
- A similar problem exists, although to a lesser degree, for mortgages. Where those infected cannot get mortgages because the lender will not recognise the security of income and/or demands life assurance, the Government should provide confirmation of income and/or a scheme of assurance or the equivalent as above.
- Many carers of those infected have given up their own earning capacity over years or decades and are now themselves in serious financial difficulty. The Government should provide independent support to such carers on a similar basis to that on which it supports those infected.
- Dependants and widows of “first” families where an infected person has remarried are currently excluded from the payment scheme. Where appropriate they should be included.
- Psychological and long-term counselling support should be provided as needed for infected persons and their families. Given the sensitive circumstances for individuals needing such support, the channel of application should be designed to be sympathetic to their psychological needs and dignity.
- There are discrepancies between the payment regimes of the Caxton Foundation and the Macfarlane Trust; these should be levelled up so that the basis of payment is closely comparable.

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- Those affected can spend excessive time accessing urgent medical care. The NHS should provide a “Platinum Card” to those affected and provide training to ambulance and Accident & Emergency staff to recognise the card and provide care accordingly.