

HEPATITIS C BRIEFING FOR THE PRIME MINISTER - 9 JUNE 1995

We have no plans to compensate those who may have been infected with Hepatitis C. We do not accept that there has been negligence.

I have great sympathy with those who may have been infected with Hepatitis C through NHS treatment. Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time.

We see a clear distinction between the plight of patients infected with HIV as a result of NHS treatment and those infected with hepatitis C.

We accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and we made provision for them because of their very special circumstances. Those affected were all expected to die very shortly and were subjected to significant social problems, including ostracism. In the case of the infected haemophilia patients, the problems of HIV were superimposed on the health, social and financial disadvantages they already suffered as the result of their hereditary haemophilia.

The Health Departments are considering a range of potential initiatives to improve the

understanding, treatment and management of hepatitis C. This could include encouragement of research into the condition and guidance to the NHS on best practice where there is a clinical consensus.

It is the Government's view that this provides the most effective use of resources. Only in this way can the impact of the disease on individual patients and their families be effectively minimised.

The Department of Health is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus.

UK blood services are some of the safest in the world, and since September 1991 when a reliable test became available, all blood donations have been tested for the Hepatitis C virus. Prior to that date some recipients of blood transfusions may have been inadvertently infected, although the chances of this in any one case are extremely small.

The Government have accepted the recommendation of the Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation for a UK wide look-back exercise, to identify and follow up people who may have been put at risk of HCV infection.

Arrangements have been made to trace, counsel and - if necessary - treat those who may have been infected through blood transfusions . We shall do all that we can to care for patients who have been infected through counselling and, where appropriate, treatment. A freephone helpline has been set up.

#### **BULL POINTS**

A wider programme is being considered to identify a range of initiatives to help improve the understanding, management and treatment of Hepatitis C.

Screening was introduced in September 1991. The first anti-hepatitis C tests became available in late 1989. These first tests had too large a number of false positive and false negative results and no satisfactory confirmatory tests were available. Expert advice was that these tests should not be introduced because of these deficiencies.

Screening was introduced in late summer 1991 when satisfactory kits became available together with confirmatory tests.

Until recently, as there was no effective treatment, to inform people they were at risk, when there was nothing that could be done about it, would increase distress without any benefit. In addition a look back to identify recipients of blood transfusion who are at risk would have been technically difficult.

There is now some confidence that many, but not all, recipients of blood infected with Hepatitis C can now be identified and Interferon alpha has been licensed for the treatment of chronic hepatitis C. This may be of help to some people.

## **BACKGROUND NOTE**

About 3000 non HIV people with haemophilia and possibly a further 3000 people who had blood transfusions prior to September 1991 (although the figures for blood transfusion people could be very much higher) are believed to have been infected with HCV as a result of NHS treatment. The Department has denied negligence and Ministers have refused calls for compensation.

It has been known for at least five years that some people will have been infected through NHS treatment and we have expected at any time a campaign to be mounted along the lines of that for HIV. In recent months there has been increased media interest and a series of EDMs, an adjournment debate, and a large number of PQs and PO cases. Writs have been taken out against a former regional transfusion centre and we are aware of others being prepared. Panorama screened a programme on HCV and blood transfusions on 16 January 1995. In the view of the Department the allegations made have needlessly alarmed many thousands of people who have received blood transfusions that carried no risk of hepatitis C whatsoever.

The Department cannot dispute that a some people have been infected through NHS treatment but deny negligence. Although patients receive the best treatment available based on existing knowledge it has to be recognised that not all medical interventions are risk free. Risks may be evident at the time of treatment or may be discovered later. If payments were to be offered for each such incident we would soon slip into a general no fault compensation scheme. The Government is opposed to a no-fault scheme, which would be unworkable and unfair.

### **Comparison with HIV**

The case does not have the same exceptional circumstances as did the HIV infection where those affected were all expected to die very shortly and were subjected to significant social problems including ostracism. Ministers have therefore made clear that they have no plans for a payments scheme.

The Government accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and made provision for them because of their very special circumstances. Those affected were all expected to die very shortly and were subjected to significant social problems, including ostracism. In the case of the infected haemophilia



patients, the problems of HIV were superimposed on the health, social and financial disadvantages they already suffered as the result of their hereditary haemophilia.

Hepatitis C is different to HIV. Many people infected with Hepatitis C may enjoy a long period without any symptoms appearing. 50% of sufferers may progress to chronic hepatitis with varying degrees of good and ill health. Perhaps 20% of infected patients will develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. The majority of those years will be trouble free in terms of ill health and only a small percentage will actually die of liver disease.

### **Haemophilia Society Campaign**

The Society has stressed in its press release of 14 March launching current its campaign that it is not seeking legal compensation through the courts with a view to allocating blame or liability. However the Society has said that it believes there is a clear moral case for the government to provide immediate assistance for those people with haemophilia infected with the virus.

The Haemophilia Society have also stated in their press release that over 40 haemophilia patients have died through infection with hepatitis C virus. It is important to retain a clear sense of proportions and timescales. The figures quoted by the Society relate to the 5 year period 1988 to 1993. In 1993 12 haemophilia patients died with the cause of death shown as liver disease. This was out of 126 haemophilia patients known to have died in that year. Of these 12, 8 were also HIV positive. Without seeking to minimise the tragedy these are small numbers when weighed in the balance of the good that treatment has brought to many of these and countless others.

The Society's campaign objectives are stated to be:

- More equitable treatment in financial terms between those people with haemophilia infected with hepatitis C through contaminated blood products and those infected with HIV through contaminated blood products, specifically:
- An across the board ex-gratia payment to all those infected with HCV through contaminated blood products.
- Access to a hardship fund for those who become ill and the dependants of those who die.

- As a matter of urgency, payments to those who are already ill and the dependants of those who have died.
- Adequate resources for haemophilia centres to enable them to provide the best possible treatment and care for people with haemophilia and hepatitis.
- Adequate resources for research into the prognosis and treatment of HCV.
- A public education programme that provides reassurance about the methods of transmission of hepatitis C and explains that ordinary social contact is not a means of transmission.

#### **Position in other countries**

We believe that Austria is the only European country committed to making any payments to haemophiliacs. A table is enclosed setting out the best information we can currently obtain.

#### **Departmental action**

Discussions are taking place between the Department and the Directors of the Haemophilia Centres about what needs to be done, including development of further good practise for the treatment of HCV positive haemophilia patients, and to ensure that they have ready access to treatment centres. The Department is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus.

The Health Departments have mounted a UK wide look back exercise to trace, counsel, and where necessary treat those who may be at risk of hepatitis C through blood transfusion. The start of the exercise was announced on Tuesday 4 April.

DH are considering other steps which could be taken to ensure for example that: treatment is made available and that any additional research which might be required to improve the understanding, treatment and management of those affected be investigated. DH is also giving sympathetic consideration to appropriate requests for support from any self help groups which might be able to provide cost effective assistance to their members.

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