



HAEMOPHILIA AND HEPATITIS C - THE CASE FOR FINANCIAL RECOMPENSE

**Special briefing for meeting with the Secretary of State, Frank Dobson MP on
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Caring for people with haemophilia and other bleeding disorders

Introduction

More than 3,100 people with haemophilia in the UK are estimated to have been infected with the hepatitis C virus (HCV) through the use of contaminated blood clotting concentrates given as part of their NHS treatment. Almost all those who received treatment before 1986 (when viral inactivation procedures were introduced) have been infected. This includes, not only those with severe haemophilia who require regular treatment, but many of those with mild or moderate haemophilia who may have been treated only once or twice in their life. It also includes men and women with the related bleeding disorder von Willebrand disease, who have received clotting factor concentrates, and also some carriers.

Similarities between HIV infection and HCV infection

More than 1,200 people with haemophilia were infected with HIV through their NHS treatment with contaminated blood clotting concentrates prior to the introduction of viral inactivation procedures in 1986. In 1989 the Government accepted the principle of providing financial support for all those infected with HIV and established the Macfarlane Trust to fulfil this role. Payments totalling nearly £80m (including several top-ups to the original £10m fund) have been made on an ex gratia basis through the Trust to people with haemophilia infected with HIV. These payments were a combination of lump sum payments, regular monthly payments and one off single payments. The Government made this settlement not on the basis of accepting any legal responsibility, but rather that it felt it had a moral responsibility to provide financial help to those who had been infected with HIV as part of their NHS treatment.

Those people with haemophilia infected with HCV were infected at exactly the same time and by the same route as those infected with HIV, ie by contaminated blood products given as part of their NHS treatment prior to 1986. We believe that the moral responsibility accepted by the Government for those infected with HIV applies equally to those infected with HCV. It is irrelevant for these purposes whether or not they were receiving the best possible treatment at the time. Over 270 MPs of all parties signed an Early Day Motion in the last Parliamentary session supporting the Society's view. At present no financial help has been made available to the 1,900 people infected with HCV who are not co-infected with HIV. This inequity is graphically demonstrated by the following case of three brothers with haemophilia.

Two of the brothers became ill and died as a result of their HIV infection; their dependants received financial support from the Macfarlane Trust. The third brother escaped HIV infection, but was infected with HCV and died as a result. His family have received no financial help from the Government.

The exact number of people with haemophilia in the UK infected with HCV is unknown. The figure of just over 3,100 comes from the UK Haemophilia Centre Director's Organisation (UKHCDO) and is based on the number of people treated with clotting factor concentrates before the introduction of heat treatment in 1986. Everyone with haemophilia or von Willebrand disease registered at a Haemophilia Centre should by now have been tested for HCV and so the exact number infected can easily be calculated.

Medical impact of HCV infection on the lives of people with haemophilia

HCV attacks the liver and is potentially life threatening. Although the prognosis for HCV is unclear, there is a consensus amongst current medical opinion that up to 80% of those infected will develop chronic liver disease; between 10% and 20% of these will develop cirrhosis of the liver and a number of these will develop liver cancer. While it is estimated that the progression to severe liver disease can take between 20 and 40 years it should be pointed out that some people with haemophilia have already been infected for 20 years.

There is reason to believe that the prognosis may be worse for people with haemophilia infected with HCV because

- a) they may have been infected continuously over a period of 10 years prior to 1986,
- b) they may have been infected with more than one strand (genotype) of HCV,
- c) most have been infected with genotype 1, which appears to be less responsive to treatment with interferon alpha, the only licensed treatment for HCV in the UK,
- d) interferon alpha's success rate with people with haemophilia and HCV is significantly lower than for others infected with HCV.

Information on mortality and morbidity is limited. Data collected by the UKHCDO suggests that up to 1995 over 50 people with haemophilia have died from liver failure or liver cancer. However, other unpublished studies suggest that liver disease may be a major contributory factor in the deaths of a much larger number of people with haemophilia. There is only limited data available on the numbers with cirrhosis as this can usually only be determined by a liver biopsy which is not a recommended procedure for people with haemophilia. Other major symptoms of progressive liver disease are lethargy and fatigue, which are not easily measured.

Social/economic impact of HCV infection on the lives of people with haemophilia

In December 1995 the Society submitted to the Department of Health the "Hepatitis C Impact Study: Interim report", which detailed the results of six month's research into the lives of people with haemophilia infected with HCV and their families. The research examined the overall impact on people's lives - the effects on their employment, their education and their family relationships - rather than their health in isolation.

A major problem facing all those infected is that it is not yet possible to predict which individuals are likely to develop cirrhosis or liver cancer. While some will remain well, they all have to face this uncertainty about their future health and the stress and anxiety that it creates.

Regardless of their current health, all those who are HCV antibody positive will be unable to gain life insurance except at prohibitive rates. Those with young families or other dependents will not be able to have the peace of mind that goes with knowing their dependents will be catered for after their death.

The risk of transmission to sexual partners is small, but nevertheless real. This is a worry both for those in long-term relationships and those entering new relationships. Similarly, there are fears of infecting an unborn child and this is discouraging some couples from having children and adding an extra anxiety to those who decide to go ahead and have a child. Young adults are worried that they may not be able to settle down and have a family.

Everyone infected is faced with the possibility of infecting other members of their household through blood to blood contact. HCV is thought to remain infectious in dried blood for several months.

For those whose health is affected by the infection the biggest problem is reduced income from having to reduce their hours of work, give up opportunities for promotion, take a less demanding job and in many cases to give up employment altogether. The tiredness resulting from HCV has made many physical and mental activities impossible. Those affected in this way will become increasingly dependent on state welfare benefits.

As well as losing income, many also face increased costs as a result of the infection. The main extra costs arise from increased expenditure on medicines and dietary requirements.

The education and schooling of many teenagers has been affected by HCV and this will have an impact on their future life chances and job opportunities. There is little for them to look forward to. Many are experiencing deep psychological problems as a result of their infection.

Unfortunately, many also face discrimination and ostracism at work, at school and in society generally because of the ignorance and lack of general understanding about HCV.

A number of those infected have already died leaving widows and other dependents to fend for themselves.

The impact varies between individuals depending on their personal circumstances, but many families and relationships are being pushed to breaking point by the stresses and anxieties created by HCV. For those who are becoming progressively more ill the problems are even greater.

It is hard to appreciate the full impact on people's lives. Having haemophilia is bad enough; having to cope with another life threatening condition imposes a terrible burden. The enclosed testimonies highlight the impact of HCV on a number of individuals and their families.

CONCLUSION

People with haemophilia infected with HCV were infected in the same way and at the same time as those who were infected with HIV. They are experiencing many of the same problems as those infected with HIV. On moral grounds they should therefore be offered similar financial help. The Society would like to see the principle behind the HIV settlement extended to those infected with HCV.

Financial support would help alleviate some of these problems. Payments could be used both to target specific identified needs as well as to provide resources to allow infected individuals to regain some control over their lives. Different forms of payment could be used to meet the complex and changing needs of those infected.

a) Across the board lump sum payments

These have the advantage of giving the individual some autonomy and control over their lives by allowing them to spend the money how they feel is best. It would allow them to provide some financial security for the future. These payments are easy to administer and require very little bureaucracy. They would be a recognition of the problems faced by all those infected, such as uncertainty, discrimination and fear of infecting others.

b) Access to a hardship fund

A hardship fund has the advantage of being able to target help to those with specific needs arising from their HCV infection. It has the flexibility to make one off single payments, for example to pay for respite care, whereas regular monthly payments could help top up income reduced by the need to work fewer hours because of illness. A hardship fund could also make payments in specific circumstances such as bereavement or for extra heating in winter.

Any system that is established must be able to respond to the changing needs of those infected and their families. We have been able to identify some of the current needs, but these are likely to change in quantity and type as the illness progresses in a larger number of people.

Some of those infected have already died leaving dependents trying to cope. Others are ill and unable to work. Many are unable to participate actively in everyday social activities. Although there are priorities for immediate financial help, all those who have been infected deserve some level of financial support to help them cope with the uncertainty of living with a potentially fatal virus.

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