TBC6

Q & A

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(a) payments

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I. QUESTIONS SPECIFIC TO HAEMOPHILIACS

WHAT INFORMATION IS COLLECTED ABOUT NUMBERS OF HAEMOPHILIA PATIENTS AFFECTED?

Figures are not collected centrally for haemophilia patients who have contracted hepatitis C through contaminated blood, or for those who have died. I understand from the United Kingdom Haemophilia Directors that of 126 haemophilia patients known to have died in 1993, 12 showed the cause of death as liver disease of which hepatitis C may have been the cause.

HAEMOPHILIA PATIENTS INFECTED WITH HEPATITIS C

Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses in 1985. We believe this number to be approximately 4,000 (including 1,00 who also infected with HIV).

These patients received the best treatment available in the light of medical knowledge at the time.

WHAT WILL BE DONE TO ASSIST THE HCV INFECTED HAEMOPHILIA PATIENTS?

Discussions are taking place between the Department and the Directors of the Haemophilia Centres about what needs to be

done to develop good practice for the treatment of people with haemophilia who are also HCV positive and to ensure that such people have access to treatment centres.

WILL DH SUPPORT SELF HELP GROUPS

The Department is already supporting an initiative by the Haemophilia Society to undertake research into the best way to support its members who are infected with HCV.

Recombinant Factor VIII (If the Minister really is serious about trying to avoid further infection with blood products, why does he not press for universal treatment with recombinant Factor VIII).

The safety of blood products depends on a number of factors which taken together reduce as far as is possible the risk of viral transmission. These include screening of donors, testing of donations, plasma pool testing and the ability of manufacturing processes to remove and inactivate viruses both enveloped such as hepatitis C and HIV and non-enveloped such as hepatitis A. [It is accepted that parvovirus is unlikely to be destroyed by most of these processes, but this is an extremely common infection which is usually asymptomatic or mild in most individuals.] Recombinant Factor VIII that is

currently available does in fact use albumin which is a blood product as a carrier. It is also significantly more expensive than plasma derived Factor VIII, and clinicians need to be convinced that the extra costs involved have demonstrable benefit.

Why not self-sufficient in blood products ?

The UK is self-sufficient in blood and many blood products. However, for some, such as Factor VIII, commercial products which satisfy liscencing conditions are used. It is up to clinicians whether to use UK or imported products.

II. QUESTIONS SPECIFIC TO RECIPIENTS OF BLOOD TRANSFUSIONS

NUMBERS OF BLOOD TRANSFUSION RECIPIENTS INFECTED WITH HEPATITIS C

Some 3,000 infected patients who are alive today are likely to be identified by the look back exercise.

"LOOK BACK" TO TRACE BLOOD TRANSFUSION RECIPIENTS

The UK blood services are currently undertaking a look back exercise to trace counsel, and where necessary treat those at risk. Records of those donors identified as hepatitis C positive after September 1991 are being checked and recipients of their previous donations are being traced. This system of course will not identify the unknown (?large) number of hepatitis C donors who have not donated blood after Setpember 1991 and the recipients of that blood.

We shall do all we can to assist those who have been affected in this way.

BULL POINTS

1. Government currently considering how best to offer support and help to those infected with hepatitis C.

2. The Department is already supporting an initiative by the Haemophilia Society to undertake research into the best way to support its members who are infected with Hepatitis C.

3. Safeguards - deferral of at risk donors, testing of donations, virucidal steps - kept under review.

4. Voluntary donor system, among best in the world, underpins safety of blood supply.

For those infected by blood transfusions rather than haemophiliacs

5. Testing of all donations introduced September 1991 when reliable test kits available

III. QUESTIONS COMMON TO ALL THOSE INFECTED WITH HEPATITIS C

(a) PAYMENTS

WHAT PLANS DOES THE GOVERNMENT HAVE TO MAKE SPECIAL PAYMENTS TO THOSE AFFECTED?

We have great sympathy for those infected with hepatitis C as through blood or blood products, but have no plans to make special payments

WHY TREAT DIFFERENTLY FROM PATIENTS INFECTED WITH HIV THROUGH NHS TREATMENT?

We accepted that the patients who, tragically, contracted HIV through NHS treatment were a very special case and the Government 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.

COSTS OF PAYMENTS

If an exception were to be made for the patients who may have been infected with hepatitis C through blood or blood products there would be others who would argue that they too were deserving.

GOVERNMENT HELP FOR THOSE INFECTED WITH HEPATITIS C

The Government is currently considering how best to offer help and support for those infected with 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.

WHY NOT INTRODUCE NO FAULT COMPENSATION FOR MEDICAL ACCIDENTS

The Government are opposed to a no-fault compensation scheme, which would be unworkable and unfair. It would also divert money, possibly large sums, which could otherwise be available for other purposes within the NHS.

VACCINE DAMAGE PAYMENTS

The scheme set up under the Vaccine Damage Act does not provide a precedent for special help for those who have contracted Hepatitis C through blood or blood products. Vaccines are given to the healthy as a matter of public policy. On the other hand recipients of blood or blood products are given this treatment for their own benefit in the normal course of medical care for their disorder.

(b) **QUESTIONS ABOUT HEPATITIS C, TESTS ETC**

HEPATITIS C AND ITS SEVERITY

Many people infected with HCV may enjoy a long period without any symptoms appearing.

Perhaps 20% of infected patients will develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. A much smaller number, about 1% may progress to liver cancer.

WHY WAS HEPATITIS C NOT ELIMINATED BEFORE IT GOT INTO THE BLOOD SUPPLY?

In the absence of any reliable test for HCV the only way to safeguard blood was to limit those from whom blood was taken by a system of self deferral.

This excluded those known to be suffering from hepatitis or any other liver disease; drug misusers; and men who had sex with other men.

WHEN WAS ROUTINE SCREENING FOR HCV INTRODUCED?

Screening was introduced in September 1991. The first anti-

hepatitis C tests were reported in the literature in March 1989 but did not become available until later that year.

WHY WAS ROUTINE SCREENING NOT INTRODUCED IN 1989?

Expert advice was that these tests should not be introduced because of these deficiencies.

These first tests had too large a number of false positive and false negative results and no satisfactory confirmatory tests were available.†

The Department of Health funded several trials of the first and second generation anti-Hepatitis C test kits. Screening was introduced in late summer 1991, following advice from the Advisory Committee on the Virological Safety of Blood (ACVSB) that satisfactory kits had become available together with confirmatory tests.

WHICH OTHER COUNTRIES DID INTRODUCE HCV TESTING BEFORE BRITAIN?

We do not have precise details of the date at which each country introduced Hepatitis C testing. We do know that some did introduce testing before the UK.

But it must be remembered that in some of these cases the

incidence of Hepatitis C in donors is considerably greater than in the UK; also in UK the general health of donors is the best in the world.

[IF PRESSED on why we did not screen out additional blood during the period 1989 and 1991 as the Panorama programme on 16 January showed Belgium did by using a Polymerase Chain Reaction (PCR) Test:

The expert committee, which advises ministers on these issues, discussed at the time the course of action pursued by the Belgian authorities. The view of the committee was that neither the screening test nor the PCR confirmatory test should be introduced at that time because of deficiencies, particularly in the detection of false negatives.]

PEOPLE BEING DENIED ALPHA INTERFERON

Prior to the licensing of the 2 brands of alpha Interferon for treatment of patients infected with hepatitis C (November 1994 and January 1995) purchasers were often unwilling to pay for treatment using this unlicensed drug. Treatment is expensive (approximately £5000) and clinicians must decide in individual cases whether it is appropriate to prescribe this drug. Only 20% of infected individuals are likely to have long-term benefit, and it is suggested that treatment works best in the early years following infection. The drug has unpleasant

side-effects and should not be used when the patient already has cirrhosis or severe liver damage.

IV. GENERAL QUESTIONS ABOUT THE BLOOD SERVICE

REORGANISATION OF THE NATIONAL BLOOD SERVICE

I have received revised proposals from the National Blood Authority following its consultation on its proposals for the future organisation of the National Blood Service. I am considering these [and hope to be able to announce my conclusions shortly].

FAULTY BLOOD BAGS (TUTA)

The National Blood Authority is urgently investigating the recent problems with Tuta blood bags. All stocks of Tuta bags, and blood in such bags, have been withdrawn by the National Blood Authority. This was only some 20% of the total. Blood donors should keep their appointments to help keep up blood supplies, and meanwhile blood is being moved round the country as needed to meet demand.

[Risks of contamination of blood are very low. Should any infection result it is likely that signs will be apparent very quickly, so those who have previously received blood need not be concerned. (We know of only one possible case so far.]