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To: SofS

From: Christine Corrigan HSD1

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Haemophiliacs and Hepatitis C

1. You have asked officials to prepare a letter to Downing Street on the issue of a special payments scheme for those haemophiliacs infected with hepatitis C. I am sorry that, due to other matters arising on the blood front, I have been unable to respond to that request earlier.
2. There are a number of issues which need to be determined before we can prepare the letter:

(2.1) Scope of the scheme

a) Do you wish the scheme to apply to haemophiliacs only, or to all patients infected with hepatitis C through NHS treatment?

Limiting the scheme to haemophiliacs would be very difficult to justify on equity grounds, and there have already been a number of representations in support of the wider group infected through transfusions. However, if the scheme were opened up to non-haemophiliacs, this would more than double the numbers eligible.

04/09/97

b) Would you wish widows and dependents to be able to qualify for help?

Many of the representations have referred to the hardship suffered by the widows and former dependants of those who were infected with hepatitis C via blood/blood products, but who have since died. (The HIV scheme was opened to widows on the premiss that the likelihood of sexual transmission of HIV was strong, whereas in the case of hepatitis C this is believed to be infrequent.)

c) In earlier discussions you indicated that you would not wish the scheme to cover those who have already received payments under the HIV scheme - Is that still the case please?

According to the Haemophilia society's own figures, this will leave approximately 3,600 haemophiliacs who would qualify on grounds of hepatitis C alone (three times the number infected with HIV). Appendix A shows some comparative numbers of people with hepatitis C/HIV to put this in context.

(2.2) Extent of financial assistance to be offered

a) Would you wish to offer a limited scheme or parity with the HIV scheme?

The Haemophilia Society have made it clear that they would view anything less than parity with the HIV scheme simply as the first step in a "staged" award. The important point, as they see it, is that the Department is seen to accept the principle of "moral liability". Parity with the HIV scheme would cost approximately £400m for all those infected and £220m for haemophiliacs only.

b) If you did wish the scheme to be limited, how would you wish this to be achieved?

A limited hardship fund open to haemophiliacs only and operating on similar grounds to that offered to those with HIV could cost around £7.5 -10 million. However, that scheme is based on the medical progression of the disease. As the attached note (Appendix B) from the Eileen Trust (which runs the HIV scheme) indicates, to try and do something similar in respect of hepatitis C would present a formidable administrative and medical task. The scheme would be virtually impossible to contain and costs would inevitably escalate.

The alternative would be to allow applicants to qualify solely on the grounds of hepatitis C infection, irrespective of the effect on their physical well-being (and some may remain perfectly well), and to limit the amount for which any single individual (and their family) might qualify. The potential costs would depend on the sum at which payments were "capped".

(2.3) Administration of the scheme

The HIV scheme for haemophiliacs is administered by a Trust whose running costs are met from Section 64 grants (£181,000 this year). One option for the proposed scheme would be to expand that Trust to take on the hepatitis C work (what that would mean exactly in real terms would depend on the terms of the hepatitis C scheme envisaged). Alternatively you might want a separate Trust set up, ?

(2.4) Grounds for special treatment

The Haemophilia Society have made it clear that they do not allege negligence; their claim is based on the Department's "moral liability". There are, as you know, other patient groups pressing for payments on a no-fault basis. Both M(PH) and PS(C) have recently emphasized in Parliament the policy that compensation should only be paid where legal liability has been established, and that the key objective for the Department should be to spend as much of its resources as possible on direct patient care. You recently made that point in a letter to the BMA about reducing the threat of litigation in the NHS.

Clearly, if we are to avoid a flood of claims from other patient groups we will need to cite haemophiliacs/all those infected with hepatitis C as a "special" group. This could be difficult when, as the note from Dr Mark Winter (Appendix B) suggests "the vast majority of those infected remain extremely well". Those infected with HIV were, as you know, cited as an exceptional group because of unique features relating to infection - not least the considerable stigma attached and the very short survival period anticipated. It would be helpful if you could indicate on what grounds you would wish to make this group a further exception. This will be particularly important for any approach to Treasury as officials there will be aware of an understanding reached under the previous administration that the HIV scheme would be a one-off scheme and that the Department would resist similar future claims. Following recent inaccurate press reports, Treasury officials expressed some concern that we might be considering a more general no fault scheme.

We will also need to be able to explain how, having accepted the case for payment in respect of HIV and hepatitis C, we propose to resist any future claim in respect of nvCJD.

(2.4) Wider implications

The Department's policy on the handling of non-negligent harm is based on the common law, and is consistent with practice across Government and in the public sector generally. A move from that position could well have implications for other Government Departments or bodies, including the LCD which has yet to take a formal view about Sir Peter Middleton's recommendation, as part of his report on legal aid, that no fault arrangements be considered. Would you wish to consult other Departments, including the Treasury before you write to the Prime Minister?

Possible alternatives

3. If the Government wished to offer haemophiliacs with hepatitis C additional financial or other practical support without setting up a separate Department of Health scheme, there might be other possibilities. One option might be an additional income support premium for those unemployed or incapable of work. Although unlikely to be

greatly welcomed by the Haemophilia Society, this would have the dual advantage of focusing the extra resources on those most in need and of using the current administration to deal with the additional payments, rather than having to create a new bureaucracy. Another option might be to combine such a premium with a tax credit scheme for those in work. One advantage of such schemes would be that in distancing the scheme from the Department of Health, it could be argued that the Department was not accepting liability. However, other groups pressing for compensation, and possibly other commentators, may regard this as a fine distinction. Would you like us to explore the possibilities further with officials in the relevant Departments?

4. The Haemophilia Society have recently written to us (see Appendix C) about the reduction in their Section 64 grant this year (they are receiving £100,000 less than last year). This could well affect the practical support services they currently provide for those with hepatitis C. They would also like to set up an information and education project for young haemophiliacs with hepatitis C. This would aim to identify how the Society can best help such young people to cope positively with the impact of the infection on their current lives and future educational and employment expectations. The Society are currently working up a funding bid for that project. One option might be for Ministers to consider giving the Society an undertaking that they will have first call on any further Section 64 money which might become available in year (through programme slippage) ?

Action

5. Given the wide range of policy issues this matter raises, we would welcome an early meeting to clarify the details and enable us to prepare an appropriate draft letter to Downing Street.

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