MS(H)

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cc: see attached

PEOPLE INFECTED WITH HEPATITIS C THROUGH BLOOD AND BLOOD PRODUCTS

Purpose

1. When we met in September to discuss the campaign to compensate haemophiliacs with hepatitis C, you took the view that compensation for this group was not appropriate but asked us to investigate:

(i) ex gratia payments for people infected with hepatitis C through blood after the introduction of the Consumer Protection Act 1987 (CPA) who, on the basis of this year's High Court judgement, would have received damages had they gone to court. These people are now caught by a time bar preventing them taking their own legal action under the CPA;

(ii) a care package for haemophiliacs with hepatitis C on the lines of the one developed for people with CJD.

Ex Gratia Payments

(i) Size and cost of scheme

2. The National Blood Authority identified 679 people in England infected with hepatitis C through blood transfusion before the introduction of screening for the virus in September 1991. 469 of these were infected after the introduction of the CPA and, of these, 114 received damages from the High Court. This leaves 355 known individuals who missed out on the litigation. If we give, say, £10K to each to these (the lowest amount awarded by the court) the cost would be £3.5m.

3. In addition, it has been estimated that around 10,000 people may have been infected with hepatitis C through blood transfusion between 1980 and 1991. Around half of these would probably have died from other causes within a year of infection (based on the average life expectancy of transfusion recipients). So, at a guess, there may be up to 2,000 other people infected with hepatitis C through blood post CPA who could come forward if a scheme is announced.

4. We are therefore looking potentially at a two-part scheme:

- an initial payment of £3.5m to those individuals identified by NBA as having received hepatitis C infected blood;
- further payments, perhaps spread over a number of years, to people identified as having hepatitis C where infected blood is the probable cause. This process may be accelerated if it is decided following consultation on the Department's

hepatitis C strategy next year to screen people who have been exposed to known risk factors for the virus. The total cost may be up to £20m but in practice is likely to be rather less, as a proportion of people will die of other causes before hepatitis C is diagnosed and others will never discover that they have the virus. [Although there is unlikely to be any direct evidence linking these individuals' hepatitis C infection with blood, there are precedents for schemes which award payment if the person has not been exposed to other known risk factors, eg injecting drug use.]

(ii) Argument

5. There is no liability on Government to make such payments, and we have not been able to unearth a precedent for this type of scheme. There is arguably not even a moral case for making these payments as the 355 people knew they had hepatitis C from blood before the time bar came down and could have litigated had they been willing to take the risk. If anything, the moral case is slightly better for those in the second group who remain ignorant of their infection and will never have the opportunity to litigate.

6. We also need to consider what precedents such a scheme might set for other litigation against the NHS. We asked the NHSLA for examples and they came up with one that was directly relevant. The East Devon breast screening programme recalled some 2000 women. It was discovered about 250 has a realistic chance of success in the courts but only 78 took action and received damages; the others did not.

7. Whatever the merits of the arguments for ex gratia payments in this cases, any payments to transfusion recipients with hepatitis C will be seized on by others and will be seen as setting a precedent in the settlement of other group actions.

8. Such a scheme would also be perceived by haemophiliacs with hepatitis C as a slap in the face for them and would create an enormous amount of anger and resentment. It would also weaken the Government's argument for not compensating the haemophiliacs, namely that the NHS does not make payments in cases of non-negligent harm or where there is no legal basis for doing so.

9. It should be added that no money has been identified that would allow us to make these payments. If a scheme were to be introduced within the next 18 months, money would have been found from within existing Directorate SR funding envelopes. We would also need to include a late bid for funding in SR2002.

Summary/Conclusion

10. We would not advise Ministers to make ex-gratia payments as proposed on the grounds that:

- it would set a precedent for settling litigation against the NHS in other areas;
- it would take the Government a step closer to no fault compensation and pre-judge the outcome of the CMO's Advisory Group on Clinical Negligence;

- it would inflame the situation with the haemophiliacs and weaken the Government's arguments for resisting their campaign for compensation.

11. However, the position faced by people infected with hepatitis C through blood transfusion (who can only win damages they are entitled to by going to court but find themselves timed-out) lends support to the argument for some kind of limited no fault compensation scheme. You may therefore wish to draw this to the attention of the Advisory Group on Clinical Negligence as an example to consider as part of their deliberations.

Care Package for Haemophiliacs with Hepatitis C

(i) CJD Care Fund

12. The CJD care fund operates by providing each patient with a dedicated care package. The fund (a notional £1 million) is used to pay for those elements of the package that cannot readily or speedily be provided by local health and social services. Those that benefit are mostly younger patients being nursed at home through the terminal stages of their illness. The fund is needed because the speed at which CJD progresses means that the system can't always cope. It is there as a back-up only and is not intended to undermine existing services.

13. Such a package is important for CJD because of the rapid progression of the disease (the gap between first symptoms and death is on average 13 months but can vary from 6 to 39 months). It is also practicable because of the relatively small number of patients involved. We understand that 10 patients with vCJD are alive at present making individually tailored care packages a realistic aim.

(ii) Haemophiliacs with hepatitis C

14. By contrast, hepatitis C:

- is a chronic disease, progressing over 20-30 years (whilst remaining asymptomatic in some) and can be treated. About 20% of patients develop cirrhosis and, of these, a small number will develop liver cancer.

- affects may more patients. Estimates of the number of haemophiliacs with hepatitis C vary but data provided to us recently by clinicians shows that around 2,800 haemophiliacs still living were treated with blood products before 1986. All, or almost all, are likely to be infected with hepatitis C. There is no centrally collected information on the state of health of these people.

This raises questions about whether the CJD care package model could work with the much larger number of hepatitis C infected haemophiliacs or, indeed, whether it is necessary given the relatively slow progression of the disease.

Rudiments of a Package

15. It is possible to identify two, relatively short, periods in the course of hepatitis C infection when support might be particularly needed:

- during treatment with combination therapy, a period of up to 1 year when patients can suffer from extreme fatigue and depression;
- during end stage liver disease (mean time: about three years).

It would be more practicable for any package to focus on the 2nd of these two groups as this would cut the numbers to more manageable proportions.

16. We have spoken to Haemophilia Centre Directors who are not aware of any failure on the part of local services to provide support when it is needed. This is also not a concern of patients who complain of financial hardship caused by the disease (through inability to work) rather than lack of health and social services support. That said, there are additional services that might be provided to improve the quality of life of these patients and their families:

- help for those with hepatitis C in coping with the side effects of treatment, such as depression and chronic fatigue and with lifestyle changes such as diet, adhering to drug regimens etc through improved counselling provision;
- support for families and carers, eg respite care; child care;
- advice/support on welfare rights. For example, we have heard from patients that doctors conducting examinations for the Benefits Agency are not always aware of hepatitis C and its possible impact on capacity for employment;

17. The Department's Hepatitis C Steering Group is considering these social care issues for all people with hepatitis C. You may therefore prefer to wait for the Group's report in January before taking any further action. The advantage of addressing these issues for all people with hepatitis C, not just haemophiliacs, is that it avoids accusations of setting up a two-tier system.

18. There is, however, other action we could take in the meantime if you wish:

- we could re-visit the £2m included in SR2002 to support implementation of the hepatitis C strategy with a view to increasing the number of specialist nurses/counsellors to address the first two needs identified at para 16 above;
- consider what further initiatives the Department could fund through the Haemophilia Society (we are currently funding the Society to investigate the need for counselling support for haemophiliacs with hepatitis C). We are meeting the Haemophilia Society on 30 November and could use the opportunity for some exploratory discussion.

- provide a letter for you to send to DWP Ministers to raise the issue of haemophilia/hepatitis C awareness among DWP medical examiners (the third point at para 16 above).

Overall Conclusion

19. Are you content:

  - to hold the policy line that no payments will be made in respect of hepatitis C infection through blood and blood products except where awarded by the Courts;

  - to refer the hepatitis C litigation case to the CMO's Advisory Group on Clinical Negligence as an example when they consider no fault compensation;

  - for officials to take the actions set out at para 18 above;

  - to leave wider consideration of the social care needs of people with hepatitis C to the Hepatitis C Steering Group and the subsequent consultation paper?

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