

SCOTTISH CABINET

FINANCIAL AND OTHER SUPPORT FOR PATIENTS WHO HAVE  
CONTRACTED HCV FROM BLOOD TRANSFUSIONS ETC; SCHEME OPTIONS

MEMORANDUM BY THE MINISTER FOR HEALTH AND COMMUNITY CARE

**Purpose**

1. To agree the presentational approach for my further appearance before the Health and Community Care Committee (HCCC) on 29 January. To decide on the type of ex gratia payment scheme the Executive would wish to establish if associated legal and social security issues can be resolved.

**Background**

2. I have been asked to appear before HCCC again on 29 January. UK Ministers, however, have yet to reach a conclusion on the issue of devolved powers.

**Devolved Competence**

3. We understand the view of DWP officials is that a scheme to make ex gratia payments is reserved on the grounds that it would provide assistance for social security purposes to individuals who "qualify by reason of old age, survivorship, disability, sickness, incapacity, injury, unemployment, maternity or the care of children or others needing care" (within the meaning of Section F1 of Part II of Schedule 5 to the Scotland Act). The next step may be for the issue to be considered by the UK Law Officers – before the Secretary of State for Work and Pensions is in a position to reply to my letter of 5 November.

**Scheme Design**

4. We are also being pressed in Parliament to be more specific on how a scheme would be designed. A difficulty in this is the variability of the health outcome resulting from HCV infection. Some individuals may never develop liver damage or symptoms, others will clear the virus and the remainder will develop some level of long-term symptoms or liver damage.

5. We expect about 16% of those infected to develop serious long-term harm within 20 years (in the form of cirrhosis, liver cancer etc). It is not possible to exclude the possibility that over a longer period this might rise to 60%. To budget for this however would be ultra-conservative – partly because the scenario is speculative but also because many of the individuals are likely to have died of other causes before reaching this stage. In any case any additional expenditure would not occur for a number of years.

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6. The Expert Group's scheme would provide payments to all those infected - including those who have cleared the virus. It would also make payments to the dependants or estates of infected individuals who are now deceased, which substantially increases the potential cost of the scheme.

7. I believe instead that the scheme should be targeted at those who are still alive and who are experiencing long-term symptoms or signs of liver inflammation. The category most seriously affected are those suffering from cirrhosis, liver cancer or liver failure. Whilst it is possible to construct a scheme that would only make payments to individuals who had reached that stage, I do not believe to is realistic or fair to do so.

8. The following options provide for payments to all those experiencing long-term symptoms or signs of liver inflammation, but with increased awards to those who develop the more serious conditions such as cirrhosis. I invite the Cabinet to confirm that this should be our approach.

The options are:

**Option 1: awards at the levels recommended by the Expert Group (£50k to all with long-term symptoms or damage; plus further £50k to those who develop cirrhosis etc).**

The estimated cost of this option would be between £22m and £44m.

**Option 2: £35k to all with long-term symptoms or damage; plus further £35k to those who develop cirrhosis etc)**

The estimated cost of this option would be between £15m and £31m.

**Option 3: £25k to all with long-term symptoms or damage; plus further £25k to those who develop cirrhosis etc)**

The estimated cost of this option would be between £11m and £22m.

[Lump sum awards are proposed because we understand it might be easier for these to be disregarded for social security purposes. The lower estimate in each case is based on payments to the 568 individuals recorded as being alive. The higher estimate also covers the possibility of payments to an additional 597 individuals (i.e. a total of 1165) thought to be alive on the basis of epidemiological estimates. I expect the take-up for the 568 group to be fairly heavily front loaded with a possible profile of 60%;30%;10% over the first three years. Take-up for the larger 1165 group is likely to be slightly less front loaded.]

9. These options all have significant financial implications. The Health Department does not have explicit provision for these costs at present, and its Reserve for next year currently stands at only £25million to meet all unexpected pressures. The PFO has already reported that the central Reserve is also severely constrained. Furthermore, because of the measures we have been taking to reduce the underspend this year, resources available from end year flexibility next financial year (which might normally be used for a one off cost like this) are likely to be less than in recent years

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10. On that basis I can only support Option 3. I would be willing to provide up to £10 million in the next financial year - 2003-04 to meet these costs, and I accept that that amount would be for the health budget to meet. But I could not find any more than required to fund this option and it would be very difficult for me even to find that amount. If any of the options are pursued, difficult decisions will be required about stopping other activities or developments, with a potential impact on Executive priorities and targets.

**Issues for the HCCC Meeting**

11. It is likely that we will be in the position on 29 January of still waiting for a view from the UK Government on the devolved powers issue. We are likely to be criticised for the length of time it is taking to resolve this. We will have to indicate that the issues are in front of the UK Government, that there are difficult constitutional and legal considerations, and that it is the responsibility of the UK Government to reach a view on these.

12. It would be helpful if I could say a little more to the Committee about the type of scheme and criteria we have in mind. I have in effect already broadly outlined to the Committee our preferred approach, and we should not at this stage be completely specific about what we propose and the costs, in case this further raises expectations of what we will be able to do. Clearly we cannot make any payments if we do not have the legal powers to do so, and we cannot make any firm statement ahead of further advice from the UK Government on this point. But I could indicate that we favour a scheme based on the principles stated in paras 7 and 8.

13. Given the state of progress, it is likely that the Committee will wish to take a report to the Parliament, probably recommending implementation of the Expert Group proposals. We will need to consider in due course our response to and handling of such a debate

**Consultation**

14. The Ministers for Finance and Public Services, and for Parliamentary Business, and the Deputy Minister for Parliamentary Business have commented on the paper. The Minister for Finance and Public Services noted that we cannot make any payments unless there are the legal powers to do so, and that there was a need for a rigorous discussion of the financial implications. The Minister for Parliamentary Business considered that there would be political and media criticism of what was proposed, and handling difficulties. The Deputy Minister for Parliamentary Business also considered there would be handling problems, and that a more detailed presentation of the financial issues was needed.

**Conclusion**

15. I invite colleagues to agree that we base our design of a scheme of payments to those who have contracted Hepatitis C from blood on Option 3, as set out in para 8 above, and to endorse the handling line for HCCC set out in paras 11 to 13.

M Ch

22 January 2003

SC(03)10

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From: Minister for Health and Community Care  
Sent: 12 December 2003 16:44  
To: First Minister; DL Cabinet  
Cc: PS/Perm Sec; PS/HD Health; DL Heads of Department; [REDACTED]; Press Health; [REDACTED]

Subject: HEPATITIS C FROM BLOOD EX GRATIA SCHEME - DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION

Importance: High  
Colleagues  
letter.doc (42 KB)

PS/Cabinet Ministers

Copy as above

**HEPATITIS C FROM BLOOD EX GRATIA SCHEME - DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION**

Please find attached note for information from Mr Chisholm. I would be grateful if this could go in your Minister's box tonight (if possible).

Thank you

[REDACTED]  
APS/Minister for Health and Community Care  
12 December 2003

Minister for Health and Community Care  
12 December 2003

First Minister

Copy to: Cabinet Ministers  
PS/Perm Sec  
Cabinet Secretariat  
Heads of Department  
[REDACTED]  
[REDACTED]

**'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION**

You will recall that we previously agreed the establishment of an ex gratia payment scheme for people infected with Hepatitis C from NHS blood and blood products. Since then the UK government has agreed that the Scottish Executive has the necessary powers under the Scotland Act and, following decisions to establish a scheme in England, Wales and Northern Ireland, it is now certain that payments can be made without recipients losing social security benefits.

Discussions have been taking place between officials of the four UK administrations with a view to agreeing a single scheme that could be administered across the UK on a common basis. I have now received a detailed proposal to that effect – which also defines proposed levels of evidence and further details on eligibility. This proposal is outlined in the annex to this minute.

It will be necessary to set up a Trust to administer the scheme and this will take some time. Also it will not be possible to amend social security regulations until the end of March 2004 and until these amendments have been made it may not be in their best interests to make payments to those who could stand to lose their benefits. However, you will see that, with effect from 29 August 2003, the proposed eligibility criteria allows for payments to be made to the dependants of an eligible person if that person dies whilst waiting for the scheme administration to take effect.

The basic scheme parameters and associated costs are unchanged from those we previously agreed and I propose indicating the agreement of the Scottish Executive to proceeding on this basis. Hopefully the other UK Health Ministers will also be in agreement, in which case I expect there to be a simultaneous public announcement in the week commencing 15 December.

**MALCOLM CHISHOLM**  
12 December 2003

## **'HEPATITIS C FROM BLOOD' EX GRATIA SCHEME – DETAILS OF PROPOSED PARAMETERS AND ADMINISTRATION**

### **SUMMARY**

#### **Eligibility and awards**

- £20,000 to people who were infected with Hepatitis C as a result of being provided by the NHS with blood or blood products before September 1991.
- £20,000 to people who have been infected as a result of the virus being transmitted from a person who themselves was infected as above.
- Additional £25,000 to people who are eligible for the £20,000 award when their condition progresses to cirrhosis, liver cancer or if they have received a liver transplant.
- No payments to those who have cleared the virus spontaneously.
- People co-infected with HIV will be dealt with in the same way as those infected only with Hepatitis C.
- People who have had a liver transplant will receive both the £20,000 and £25,000 awards.
- People who have cleared the virus under treatment will be dealt with in the same as those who still have the virus.

#### **Payments to the 'deceased'**

- No payments to dependents of people who died before 29 August 2003.
- Where people eligible on 29 August 2003 die before the scheme is in a position to make payments, awards will be made to their dependants.
- Once the scheme is in a position to make payments, awards will only be made to dependants where a claim has been received on behalf of the infected person prior to their death.

#### **Variations and conditions**

- People who have received compensation as the result of a successful legal action against the NHS (or an out of court settlement in relation to a legal action) would have that deducted from the total award.
- People who have received compensation as the result of a successful legal action against a product supplier would have that deducted from the total award.
- People who receive payments under the scheme would undertake not to institute future legal proceedings against the NHS or Ministers in relation to the situation that formed the basis of those payments.

### **Evidence**

- Generally evidence will be judged on the balance of probabilities.
- It would be presumed that claimants with Hepatitis C who have received pooled products were infected by the product. (Virtually all haemophiliacs will fall into this category).
- No requirement for invasive tests to establish cirrhosis.

### **Administration**

- Single UK scheme operating to common parameters in Scotland, England, Wales and Northern Ireland.
- Administered by a single independent charitable Trust.

[REDACTED]

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**From:** [REDACTED] on behalf of Minister for Health and Community Care  
**Sent:** 15 January 2003 09:34  
**To:** [REDACTED]  
**Cc:** Deputy Minister (McAveety) for Health and Community Care; Deputy Minister (Mulligan) for Health and Community Care; PS/HD Health; [REDACTED] [REDACTED] Keel A (Aileen); [REDACTED] First Minister; Deputy First Minister (Minister for Justice); Minister for Finance and Public Services; Minister for Parliamentary Business; Deputy Minister for Parliamentary Business; PS/Perm Sec; PS/FCSD; [REDACTED] Press First Minister; [REDACTED] Ghibaldan S (Sam); Freeman J (Jeane); Campbell D (Douglas) (Special Adviser); [REDACTED] Policy Unit Mailbox; [REDACTED]  
**Subject:** RE: Draft Cabinet paper for 22/1 meeting: Ex gratia Payments to 'HCV from blood' patients

[REDACTED]

cc. as above

**DRAFT CABINET PAPER FOR 22/1 MEETING: EX GRATIA PAYMENTS TO 'HCV FROM BLOOD' PATIENTS**

The Minister has seen your minute and paper of 14 January 2003 on the above and has made the following comment.

“I don't agree with the Cabinet Paper. There are many more options and we need one that is affordable. Also, when did we hear that DWP Law Officers had come to a view it was reserved?”

The Minister would like to have a brief meeting today at 4 o'clock. [REDACTED] will e-mail you about this shortly.

Many thanks.

[REDACTED]  
**APS/Minister for Health and Community Care**  
15 January 2003



[REDACTED]  
From: Minister for Health and Community Care

Sent: 03 October 2003 18:04

To: [REDACTED]

Cc: Deputy Minister for Health and Community Care; PS/HD Health; [REDACTED];

[REDACTED] Policy Unit Mailbox; [REDACTED]; [REDACTED] Keel A

(Aileen); [REDACTED]; [REDACTED]; [REDACTED];

Press Health; [REDACTED]

Subject: RE: Hepatitis C

Letter to HCCC re

ST'relevati...

[REDACTED]  
The Minister has seen the redrafted letter and has made a few changes and this has now issued. I have attached the revised version for your information and a signed hard copy will follow for your records.

Thank you

[REDACTED]  
Minister for Health and Community Care Office

3 October 2003



## SCOTTISH EXECUTIVE

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Minister for Health & Community Care  
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October 2003

### **Hepatitis C issues in the 1970s and 1980s**

Following receipt of your letter of 10 September, I have now seen a copy of the document cited in the recent Sunday Times and Scotland on Sunday articles and referred to in your letter of 19 September. The document in question is a report entitled "Haemophilia Directors' Hepatitis C Working Party Report for Year 1980-81" – which appears to have been considered at a meeting of Haemophilia Directors in September 1982.

The point at issue is whether this document reveals new information about what that government officials knew, and whether in particular it confirms that they were aware from as early as 1974 that treatment with blood clotting factor concentrates carried a risk of infection with what we now know as Hepatitis C.

There is no doubt that this document does confirm that haemophilia directors and the Department of Health and Social Security were aware of such a link, but I am afraid that this does not constitute new evidence. I am told there are numerous published articles in eminent medical journals, such as the Lancet, in the 1970s and 1980s that record information, interest and controversy on this issue. It is important to consider the Haemophilia Directors' report in that context.

In the early 1970s Hepatitis C infection was widely regarded as causing little harm, although there is no doubt there were some clinicians who strongly dissented from that view. As more information became available more clinicians began to voice concern – although not uncommonly the view was expressed that the benefits of the treatment outweighed the consequences of the resultant infection. Certainly up until 1985 at least there was no universal consensus that the Hepatitis C infection had serious consequences and many experts viewed it as a mild, non-progressive condition. This is recorded in the Scottish Executive's Report on Heat Treatment of Blood Products (October 2000) along with appropriate references.

From at least 1976, product information leaflets also contained statements that the risk of transmitting hepatitis could not be excluded. This information was directly available to all clinicians

involved in the treatment of haemophiliacs with these products and also to the substantial proportion of patients who were practising home therapy (40% in 1978).

These observations of what was understood at that time are also reflected in the findings, in the Irish Republic, of Judge Alison Lindsay in the 'Report of the Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters' (September 2002). In it she concludes:

"The Tribunal has formed the view from this evidence that the consensus which existed in the late 1970s and early 1980s that NANB hepatitis was relatively mild or benign did change as the results of studies became available showing the condition to have potentially serious consequences for some people infected by it. A number of experts came to regard it as a serious disease with significant long term consequences, especially and increasingly in the period after approximately 1985. That view did not, however, come to be universally held in the relevant medical and scientific communities until after 1989."

The subsidiary point made with respect to the Haemophilia Directors' Report is that there was a greater risk of Hepatitis C infection from some concentrate products than from others and, in particular, a much greater risk from commercial products than from NHS products. However, this information has to be viewed against the actual circumstances prevailing in 1982 namely the background of conflicting expert opinion on the seriousness of Hepatitis C infection, variations in the efficacy of different products in treating haemophilia in individual patients, variations in the side effects, the fact that both commercial and NHS products were licensed by the Medicines Division of the DHSS (the predecessor of the Medicines Control Agency), and the inability of the NHS to meet UK demand.

However, concern about the unknown long term outcomes from Hepatitis C infection was a driver for the initiative for UK self-sufficiency in blood products. The Scottish National Blood Transfusion Service was in the forefront of efforts to produce adequate supplies of non-commercial product.

A copy of the Scottish Executive's Heat Treatment report was placed in the Parliament's Reference Centre at the time it was made public – together with the associated references (which include many contemporaneous articles in the medical press). We should be happy to provide the Committee with copies of these documents if that would be helpful. We also have copies of other documents that show that the link between treatment with clotting factor concentrates and hepatitis infection was available to organisations representing patient interests.

I note that the Committee decided at its 16 September meeting that it needed to receive private briefing from the Committee clerks before it could usefully consider the matter further. As I have indicated above there are a number of important documents that might assist the Committee which it does not appear to have seen. I would be happy to make my officials available to assist in any briefing if that would be helpful.

**MALCOLM CHISHOLM**

**From:** [redacted] on behalf of Minister for Health and Community Care  
**Sent:** 28 October 2003 10:05  
**To:** [redacted]  
**Cc:** Deputy Minister for Health and Community Care; PS/HD Health; Press Health; [redacted]  
 [redacted] Keel A (Aileen); [redacted]  
**Subject:** RE: HCV from blood - Meeting between Melanie Johnson and Haemophilia Society [29 Oct 2003]

[redacted]

Copy as above

**HCV FROM BLOOD- MEETING BETWEEN HAEMOPHILIA SOCIETY AND MELANIE JOHNSON.**

Mr Chisholm has seen your minute of 27 March regarding a meeting between Melanie Johnson and the Haemophilia Society and has noted the lines prepared by the Department for Health and has noted the current thinking on the scheme parameters.

[redacted]  
 APS/Minister for Health and Community Care  
 28 October

*Policy briefing for  
 English Minister  
 (meeting with patient groups  
 - elephant hoops  
 28/*

**From:** [redacted] on behalf of Minister for Health and Community Care  
**Sent:** 13 November 2003 19:30  
**To:** [redacted]  
**Cc:** Deputy Minister for Health and Community Care; PS/HD Health; [redacted]  
**Subject:** RE: HCV ex gratia scheme - payments to dependents

[redacted]

Copy as above

**HCV EX GRATIA SCHEME – PAYMENTS TO DEPENDENTS**

I refer to your email of 12 November regarding the above. Mr Chisholm has indicated that he thinks option 3 is best.

Thank you.

[redacted]  
PS/Minister for Health and Community Care  
13 November 2003