The Birmingham Children's Hospital NHS Trust
Department of Haematology
Ladywood Middleway
Ladywood
Birmingham B16 8ET

Tel: 0121-454-4851 Ext: GRO-C
Direct Line: GRO-C
Fax: 0121-454-2656

FGHH/PAM

3 May 1995

Dear Maggie,

I enclose a photocopy of the proceedings of a debate in the House of Lords. In particular I would draw your attention to that said by Baroness Cumberlege on p. 866 and 867 which I have underlined. Clearly this matter needs to be taken up with the purchasers, as the representative of the government is clearly stating that treatment should be available. I trust this will help in the battle to ensure that patients who require treatment are able to get it.

Yours sincerely,

GRO-C

F. G. H. Hill
Consultant Haematologist

Enc.

Copy to:
Dr. S. Mitchell
Directorate Manager
BCH.

Copy to: ✓
Dr. M.D. Williams
Consultant Haematologist
BCH.

Copy to:
Dr. P.J. Darbyshire
Consultant Haematologist
BCH.

To:
Maggie Lever
Specialty Manager
BCH.

[15 MARCH 1995]

The McFarlane Trust

3.14 p.m.

Lord Ashley of Stoke rose to call attention to the case for expanding the role and funding of the McFarlane Trust, whose original purpose was to make payments to haemophiliacs infected with the HIV virus from contaminated blood transfusions; and to move for Papers.

The noble Lord said: My Lords, we are having the debate for two reasons. The first relates to the principle that the Government should give special protection to people who are especially vulnerable to damage from NHS treatment, particularly if they have very little choice whether to accept that treatment. That applies to haemophiliacs.

The second reason is the Minister's failure to respond reasonably to Questions in the House and her apparent inability to see the justice of people's claims. I am very sorry to have had those responses from the Minister for whom I have great respect and a warm regard. The House should not be fobbed off with unsatisfactory Answers at Question Time on issues of this kind.

Some 90 per cent. to 95 per cent. of haemophiliacs who received blood products before 1985 were infected with the Hepatitis C virus; 3,000 men and boys were given that particularly virulent virus which can lead to serious illness and death. Medical opinion is that up to 80 per cent. of those infected will develop chronic liver disease; between 10 per cent. and 20 per cent. will develop cirrhosis of the liver; and a number of those will develop liver cancer.

The progression to severe liver cancer can take between 20 and 40 years. Many haemophiliacs have already been infected for up to 20 years; and 41 people have died. Deaths now occur regularly at a rate of approximately one per month. As yet, only a small minority is seriously ill or dead. Even if we allow for those who will become infected, that will probably be a minority of haemophiliacs. I willingly and readily accept that fact. Nevertheless, it is an important minority and it is those people, and those people alone, whom we are discussing.

It was wrong for the Minister in her responses to Questions in the House to refer to the mass of other people, because my noble friend Lady Jay and myself have referred continuously, and emphasised continuously, that we are concerned only with the small minority who have become seriously ill and the families of those who have died. I want to re-emphasise that we are discussing those people, and those people alone.

There is little doubt that the likelihood of early death from HIV is greater than it is from Hepatitis C. But, whereas 1,237 men were given HIV, 3,000 were infected with the Hepatitis C virus. Regardless of numbers, the case of the people with Hepatitis C is that there is no basic difference between haemophiliacs who are critically ill and who have died from HIV and those who are critically ill and have died from Hepatitis C. The source was exactly the same; the outcome was exactly the same; the principle is exactly the same; and so the payment should be exactly the same.

There is no justification for making a payment to a haemophiliac who is dying as a result of an HIV infection and for refusing it to someone dying from Hepatitis C. Both should receive it. I believe that the case is unanswerable and that the Minister has been wrong. For that reason, and with all good will and friendliness, I am trying to bring her to account today. I hope to secure a change of mind and to receive proper answers to the questions that we have posed at Question Time. My noble friend Lady Jay and I feel most deeply about the matter and we do not wish to be fobbed off with unsatisfactory answers.

For those reasons my noble colleagues and I have put forward proposals that, having contracted Hepatitis C, haemophiliacs should be paid in a way similar to those with HIV. Your Lordships will recall that the 1,237 haemophiliacs were given £42 million by the Government after sustained pressure from Parliament and the public. That was not—and I repeat the word "not"—compensation in the legal sense. There was no question of negligence; negligence did not arise. It was an *ex gratia* payment.

I raised the issue at Question Time on 30th January and 21st February. On 21st February I specifically asked whether the Government would expand the role and the funding of the McFarlane Trust to cover those with Hepatitis C. Noble Lords who were then present will remember that in the exchanges I emphasised the fact that I was referring solely to the haemophiliacs who were critically ill or who had died from Hepatitis C. My noble friend Lady Jay specifically told the Minister that we were not asking for compensation. She repeated that fact most clearly and said that we were asking for an *ex gratia* payment. Nothing could be clearer.

My noble friend asked for an *ex gratia* payment because the basis of the McFarlane Trust is an *ex gratia* payment. It is not compensation. That is why my noble friend Lady Jay and I have emphasised, emphasised and emphasised again the fact that we are concerned with a small minority and are not asking for compensation. But the Minister continues to refer to compensation. She continues to refer to those haemophiliacs who are not seriously ill and who have not died. We are not prepared to accept those answers and I repeat that our points are put forward with all the good will in the world because we have a high regard for the Minister.

However, the Minister's response to the questions asked by my noble friend Lady Jay and myself was a reiteration of the fact that there is no question of the Government giving compensation. As I have repeated today, we were not asking for compensation. There was a *non sequitur* dialogue between the three of us. It was as though my noble friend Lady Jay and I had never spoken. I found that most difficult and that is another reason for detaining the House and putting forward the case in this debate. The Minister was knocking down an Aunt Sally that she had raised herself which, in terms of the McFarlane Trust, was not even considered, let alone pressed.

It was remarkable that when my noble friend Lady Jay repeated the fact that we were not seeking compensation the Minister, incredibly, spoke of litigation and compensation becoming a national sport portending the end of the National Health Service. She spoke of a national sport and the end of the NHS because my noble friend Lady Jay and I were asking for an *ex gratia* payment. That does not add up or make sense. That is why we are asking for reconsideration.

That floodgate type of argument is a favourite defence of beleaguered Ministers. What are the facts? We wish to discuss only the facts today. When the payments were made for HIV infection there was no flood of claims from non-haemophiliacs infected with HIV from blood transfusions. The floodgates were not opened and no new pressure for payment for medical accidents was provoked. If the Minister can prove me wrong I shall be delighted but my information is that the floodgates were not opened and there was no great pressure. I believe that people acknowledge and respect the special problems of haemophiliacs. The floodgate argument has no foundation.

I wish to repeat, and I hope that the point will be taken, that we are not seeking compensation and litigation but an *ex gratia* payment through the McFarlane Trust—just the same as the payment to haemophiliacs with HIV. However, I suggest that there is one important difference; that in this case the payment should be activated not by infection from the virus, as is the case with HIV, but by the onset of the disease. That is when people really begin to suffer because they can have the virus without suffering. That is what in earlier debates I called the "trigger mechanism". The proposal pays due regard to the differences between

[LORD ASHLEY OF STOKE]

HIV and Hepatitis C. There are differences but there is also much in common and it recognises the justice of both cases where severe illness and death are concerned.

The Minister raised yet another bogey to justify the Government's refusal to make the payments. She said that the treatment was given in good faith and without it the haemophiliacs would have died. That is right; it is undeniable. But exactly the same applied to the haemophiliacs with HIV. They too were given treatment in good faith and without it they would have died—but they were paid. Therefore, how can the Minister argue the case for the treatment being given in good faith but of the patients dying if they were not given it? Where is the logic in that argument? Perhaps today she will explain it to the House because I am a little bewildered. The haemophiliacs acted in good faith believing that the treatment would help and not damage them.

Haemophiliacs are a special group of people because their lives depend upon blood products. For them, blood transfusion is not rare but a life-saving, regular occurrence. They are excessively vulnerable to impurities in the blood. Other people may be able to decide whether or not to accept the risks involved in accepting the blood of others. Haemophiliacs cannot do so because their lives depend on it.

I suggest that this is a moral not a legal issue. These people are exceptional in their dilemma, the risks involved and the consequences. The fact that they are a small minority is a factor in their favour rather than against them. Assuming that the Minister is correct in saying that only a few will be affected, that the majority will not suffer and that drugs can help all those who do—and I accept that—the cost to the Government will be small. However, I must add that the low cost is no consolation to those who suffer or die as a direct result of Hepatitis C infection. I repeat again that we are concerned only with those people.

I conclude by saying that the Government now have an ideal opportunity to meet their moral obligations at minor cost with maximum benefit. Never has it been so easy for a government to achieve moral justice. The McFarlane Trust exists and the administrative structure is there, running very smoothly. All that is required is a little more money, a widening of the criteria and the agreement of the Government.

I repeat that I have an extremely high regard for the Minister, although I have been critical of her answers to Questions. But I hope that the Minister and her colleagues in the Government will reconsider their attitude in the light of today's debate and that they will do justice to that beleaguered minority.

My Lords, I beg to move for Papers.

3.30 p.m.

Lord Campbell of Croy: My Lords, I congratulate the noble Lord, Lord Ashley, first, on having won the ballot and secondly, on choosing this subject, which is far too large and difficult to be covered at Question Time. This is a time at which we can go into the matter in more depth.

The noble Lord admirably outlined the problems, and in particular the plight of those haemophiliacs who were infected with the Hepatitis C virus. The reason that I contribute to the debate today is that I was very concerned eight year ago with the problems of the haemophiliacs who were injected with the HIV virus. Noble Lords who were in the House at that time will remember that I was, I think, the first to raise the matter in this House in 1987.

About eight years ago it became apparent that some haemophiliacs in this country had been inadvertently infected with the HIV virus through their necessary medical treatment. The infection came through blood products which they received through the National Health Service. The HIV virus and AIDS were new phenomena at that time. No one knew about them or how to cure them and at that time it was realised that the injections had caused the virus in the haemophiliacs.

There was no question of negligence. I remind your Lordships that in 1987 and 1988 when we discussed the matter in this House everyone accepted that there was no question of negligence by anyone in the NHS because it was something completely new and unexpected.

I raised the subject in this House for the first time in November 1987. At that time the Government were clearly impressed by the case which was subsequently made inside and outside Parliament. Nearly a year later, in October 1988, in reply to another Question of mine the Government made a very welcome statement which included the formation of the McFarlane Trust. That trust was authorised to decide upon and to make *ex gratia* payments—not compensation—in particular cases. The money was provided by the Government for that purpose.

I recognise that most of those who are taking part in today's debate were not in your Lordships' House in 1987-88, including the noble Lord, Lord Ashley, but he and I have worked together for many years, especially when we were both together in another place. However, he may not be familiar with what was taking place in this House seven or eight years ago.

It was clear in 1988 that the trust was appointed to deal with very special circumstances; namely, those in which the infection would probably lead to death. The infection involved a little known illness, AIDS, for which no cure was known. It was also an illness that had a disreputable aura because it was usually caught through sexual promiscuity or drug abuse.

The number of haemophiliacs infected—all males, of course —was known. Known also was the number who had already died of AIDS by 1988. The total number who were injected with the HIV virus is 1,237 and the most recent figure for deaths is 596, which is nearly half of them. I presume that a very large majority of those deaths were caused by AIDS.

Incidentally, haemophilia afflicts men and not women. Perhaps the Minister will confirm to me that no women have been diagnosed as haemophiliacs or, if so, very rarely. Now that changes of sex are possible, statistics may be affected.

In 1986, the NHS, having discovered what was happening, introduced the necessary treatment of the blood products, which ended the possibility of infection. No NHS transfusion since 1986 will have infected haemophiliacs with the HIV virus.

In the past six years since it has been operating, the McFarlane Trust appears to have carried out extremely well the task assigned to it. I remember that when the Government announced its establishment there was some doubt as to whether it would work well and whether that was the right way of dealing with the matter. But I have heard no serious criticism of the way in which the trust has carried out its duties. I should be grateful if the Minister would comment on that when she replies to the debate.

That is no doubt why the noble Lord, Lord Ashley, proposed that it should have tasks added to the functions which it was allotted in the first place. It is a compliment to the trust and the way in which it has operated. When the noble Lord asked a Question on 21st February, he referred—although the Question did not—to the Hepatitis C virus, and it is about that in particular that he has spoken today.

I have every sympathy as regards the Hepatitis C virus but it is very different from AIDS. I recognise that both illnesses are to be avoided, but the noble Lord seemed to paint the picture that they are similar. Although Hepatitis C is a very nasty illness, it is in quite a different category to AIDS. Hepatitis C can be virtually invisible for years because few, if any, noticeable symptoms may appear. However, it damages the liver and is a cause of death in some cases, but it is not almost always a cause of death, as is the case with AIDS.

I understand that about 3,100 haemophiliacs were infected with the Hepatitis C virus before that key date in 1986, because the Hepatitis C virus was neutralised at the same time as the HIV virus. But that figure is more than twice the number of those infected with HIV, and only about 640 of those infected with HIV are still alive because of deaths from AIDS. That high rate of mortality is one of the special features of the HIV infection which led to the establishment of the McFarlane Trust.

When the trust was established it was made clear that its one purpose—indeed, its only purpose and its single mandate—was the HIV virus and the havoc that it was causing among people with haemophilia. To use a current expression, it was a one-off job. I do not know what the Government's response is likely to be today. They were not very forthcoming during Question Time a few days ago. I shall understand if the Government are not prepared to expand the functions of the trust. I shall not be surprised if they consider that it still has a great deal to do with the surviving people for whose welfare the trust is responsible.

I believe that the difference of opinion that has arisen between the noble Lord, Lord Ashley, from his speech, and myself is whether the McFarlane Trust is the appropriate and suitable body to take on that extra work. If, as I surmise, the Government consider that the McFarlane Trust is inappropriate and has enough to do without extending its activities to the Hepatitis C virus, I would ask them whether they can arrange for more to be done to help haemophiliacs with the Hepatitis C virus. By help I mean finance and resources—for example, help to provide the best possible treatment, especially with tests and medicine; in particular, Interferon, which is the medication most used for damage to the liver. I also have in mind assistance for all the associated problems arising from hepatitis and liver damage.

Whatever the Government's attitude may be to the proposal put forward by the noble Lord, Lord Ashley, will they undertake to examine sympathetically, and afresh, every way in which the lives of haemophiliacs who have been infected with the Hepatitis C virus, or any other serious disease or illness, inadvertently through NHS transfusions all those years ago can be made easier?

3.42 p.m.

Lord Addington: My Lords, I should like to thank the noble Lord, Lord Ashley, for raising the subject and also the noble Lord, Lord Campbell of Croy, for his speech. After those two speeches, I feel rather like the American senator who once said: "Everything that can be said on this subject has been said, but not everybody is yet saying it".

We are dealing with an infection that was caused by patients receiving vital medical assistance which was induced into their bodies in order to keep them alive. Unbeknown to the people who gave them that very necessary treatment, those patients acquired an infection which can lead to death. We already have the McFarlane Trust, which was set up to deal with exactly the same situation but involving a somewhat more virulent virus which will almost certainly lead to death; namely, the HIV virus as opposed to Hepatitis C.

Here is the dichotomy between the two cases: one will almost certainly kill you, while the other one, which may not kill you, will certainly do you some damage and may well lead to you actually needing support at a later stage. The Minister shakes her head. However, I am informed that it will do damage but that such damage becomes noticeable only later on. However, the noble Baroness probably has at her disposal more technical detail on the matter.

If we deny the fact that people who have been infected with Hepatitis C do need assistance, we are effectively denying what we have already agreed to as regards the HIV virus. If it is a matter of a very much smaller number of people, why cannot we give them such assistance? If the illnesses that they are acquiring do not guarantee their death, why can we not give them the assistance that they require? It is very simple. We are dealing with a much smaller problem than that which has been incurred, in exactly the same manner, as regards a much bigger problem. There is very little else to say about the matter.

I have been provided with an example of the absurdity of the situation. It is a case where three haemophiliac brothers all received treatment. Unfortunately, two of them were infected by the HIV virus because the blood products that they used had not

[LORD ADDINGTON]

been treated as is currently the case. Those two brothers died, but the third brother was infected with the Hepatitis C virus. He, also, subsequently died. The first two brothers received compensation for their loved ones and their family and assistance when they were actually ill. However, the third brother did not. What is the ultimate difference to the individual? They are dead because of an infection that they acquired through medical treatment.

As has already been said, we are not talking about compensation; we are talking about an *ex gratia* payment for something that was done accidentally while someone was trying to give another person medical assistance. That has been agreed today by both previous speakers. I shall be very much surprised if the noble Baroness contradicts that fact. If we cannot give that kind of assistance to such people, we must think very hard about why we are continually giving assistance to people who simply caught another virus through exactly the same means.

It is a question of logic which points the way towards setting up some body or providing some form of support—and here I agree with the noble Lord, Lord Campbell of Croy —indeed, it may well be necessary to establish a new body, if, for some reason, the McFarlane Trust cannot take on the extra work. It is important that such assistance should be given. As we have already accepted that anyone who has acquired the one virus needs assistance, surely those who acquire the second, and who may not require as much assistance, should also receive it.

3.47 p.m.

Baroness Jay of Paddington: My Lords, I am most grateful to my noble friend Lord Ashley of Stoke for reintroducing the subject about which I know both he and I share a joint concern. Indeed, it is the latest in his courageous and tenacious attempts to speak for the disadvantaged and those who have suffered an injustice. Perhaps my only regret this afternoon is the fact that more noble Lords have not put down their names to speak.

However, from those who have spoken thus far, I believe that we have heard a very clear exposition of what is, as the noble Lord, Lord Campbell of Croy, said, an issue which is too complicated to deal with during Question Time but which, on the other hand, I suggest is a relatively simple one. I believe that the noble Lord, Lord Addington, illustrated that most clearly in the example that he gave the House of the three brothers, one of whom had been infected with the Hepatitis C virus and did not receive any recompense, while the other two brothers who were infected by the HIV virus did.

At the risk of irritating the Minister, I should like, once again, to emphasise—and, indeed, the noble Lord, Lord Addington, is right, I do not take a different position either from him or from my noble friend on the matter—that we are talking about *ex gratia* payments and not about compensation. Like my noble friend, I too remember the Minister's replies to the Questions which my noble friend Lord Ashley tabled earlier this year. She said that she suspected the floodgates would be opened if that *ex gratia* payment was extended to those haemophiliacs who had Hepatitis C and that she also saw such operations as opening floodgates not simply on this issue but also, potentially, leading to the destruction of the NHS.

History does not relate any such floodgates being opened when the McFarlane Trust was established. It is not a question of inviting the sort of legal extravagances to which the Minister referred when she talked about the possibility of an American determination to achieve compensation for medical malpractice coming to this country. We are discussing a simple request for an *ex gratia* payment to a limited number of people who received an infection which was acquired as a result of medical treatment under the National Health Service.

The noble Lord, Lord Campbell of Croy, said—and I suspect that the Minister may repeat it—that Hepatitis C is not nearly as bad a condition as HIV and AIDS. Of course, we all accept that what one might, I suppose, call the "risk assessment" of dying from Hepatitis C, is less than that of dying from HIV infection. But I think we should not underestimate the chronic liver problems which are already being suffered by several people in this category and the potential for cirrhosis and liver cancer which has already been graphically described. I also think that if we are considering those people who already have haemophilia we should not underestimate the difficulties and unpleasant nature of that condition, which in itself may well reduce life expectancy.

But I do not think that this afternoon we are really arguing about the relative seriousness of symptoms caused by blood products which have been infected and are caused by infections contracted through NHS treatment. What we are talking about is why these people are infected. Whether or not they are ill, very ill, or dying is, in a sense, irrelevant. The point is that all of them received these contaminated blood products through NHS treatment. Some of them have been recompensed but some of them have not.

The Minister also said previously in answer to my noble friend that although there were obviously medical differences between the two groups of people who were suffering from these infections there were also social differences, and that the previous agreement to fund the McFarlane Trust had been partly based on consideration of the particular social problems which people with HIV confront. However, I have been told by the Haemophilia Society that those with the kind of infection which we are discussing this afternoon may also have to cope with uncertainty and anxiety in not knowing precisely what their condition may lead to. All of them face the worry of possible transmission to their sexual partners or transmission to an unborn child, and all will face the same kind of difficulties with life insurance and employment with which we are familiar in regard to those with HIV and AIDS.

As I have said before, this is a simple case of relative injustice in applying one standard to one group of people who have had their infection caused by one result and not to another who have contracted a different infection but through precisely the same cause. As my noble friend Lord Ashley of Stoke said, there really is a moral case here. I think the moral case is made completely and clearly for immediate hardship payments to those who are already ill and to those who are the dependants of those who have already died. I would then like to see an extension of the McFarlane Trust to provide some kind of financial adjustment and financial reward—I apologise as "reward" is an inappropriate word to use—or rather financial funding for those who have the Hepatitis C virus.

The noble Lord, Lord Campbell of Croy, said that he felt this might not be the way to do it. But it seems to me that, as my noble friend Lord Ashley of Stoke explained, the mechanisms of the McFarlane Trust are in place. It is clearly a well run and well organised fund. It would simply be a matter of an extension of an organisation, which has already justified and proved its worth, to try to act in the way that my noble friend suggests.

The noble Lord, Lord Campbell of Croy, rightly pointed out that when he was raising these issues about HIV and AIDS at an earlier stage, neither my noble friend, nor I—nor, I suspect, the noble Lord, Lord Addington, the other speaker in the debate—were Members of your Lordships' House. But I was peripherally involved in this issue when I was director of the National AIDS Trust in the late 1980s and early 1990s. I recall that the struggle to get the McFarlane Trust established, and the concerns which were expressed by many people at that time, were unpleasant and, in a sense, reflected what seemed to be almost a decision on principle by the Government that they were not prepared to act in this field. Some cynics suggested that it was only the run-up to the general election in 1992 and the enormous public outcry which by that time had surrounded the question of compensation for haemophiliacs with HIV that caused the Government finally to concede. I very much hope that we will not be faced with—

Lord Campbell of Croy: My Lords, I hope I may intervene but we do have plenty of time in this timed debate. The announcement, in answer to a Question of mine, was in October 1988. It stated that the McFarlane Trust was going to be set up. Therefore, that was rather earlier than the time of the 1992 election.

Baroness Jay of Paddington: My Lords, I am grateful to the noble Lord. I suspect he will recall that although there was a decision to set up that trust it was not funded, and payments were not made until very much later. I suspect he will find that that occurred nearly four years later. I would in any case suggest that the general point I was making—I think I am right about the timing of the funding and the payments under the trust—was as I have described and that there was a somewhat unpleasant discussion between the many people who were concerned about this issue.

I echo the admiration of my noble friend Lord Ashley of Stoke for the Minister and for the stand that she takes on many of these issues. I hope that in this case she will see that it would be a just and graceful course of action to recognise the force of the arguments which my noble friend has made so eloquently and not wait to act until there is what I suspect might be a surge of rather angry public opinion. I know that the Haemophilia Society is now co-ordinating another campaign on this subject which may ultimately force a decision on the Government.

3.56 p.m.

The Parliamentary Under-Secretary of State, Department of Health (Baroness Cumberlege): My Lords, I very much welcome the opportunity to discuss the role of the McFarlane Trust but I have to say I am disappointed that the noble Lord, Lord Ashley of Stoke, should feel that I try to fob off your Lordships' House. That is never my intention—in this debate or any other. I respect your Lordships' House and I try to be fair, honest and direct. But the noble Lord, as an experienced parliamentarian, will recognise there are occasions when a Minister gives answers which are not those sought by noble Lords opposite and which prove disappointing to them.

I agree with my noble friend, Lord Campbell of Croy, that this is a difficult and complicated question which requires more time than has been available through Starred Questions. I take this opportunity to pay tribute to him for his foresight in raising the subject as early as 1987. Perhaps I can put the noble Baroness, Lady Jay, right. The McFarlane Trust was set up in November 1987 with government funding of £10 million and the purpose of making grants and weekly payments to HIV infected haemophilia patients and their families. The work of the fund is regularly reviewed. Its income was increased by a further £5 million in March 1993.

The running costs of the trust are met by a Section 64 grant so that the whole of the capital sum is available for the beneficiaries of the trust. Since its inception the trust has given out £14 million. That is in addition to £66 million in special payments. The trust carries out its work both caringly and conscientiously and I know that both patients and the Government appreciate the way in which the trustees have approached and indeed carried out their task. My noble friend can rest assured on that.

As your Lordships will know, the trust was established to deal specifically with those haemophilia patients who were infected with HIV as a result of receiving blood products.

Your Lordships will be aware that there are many instances where people have reacted adversely to drug therapy or medical treatment given in good faith where non-negligent harm has occurred. Although those suffering as a result have pressed for government compensation, the Government have not accepted liability. In these incidents haemophilia patients received the best treatment available in the light of the medical knowledge at the time.

Contrary to the views expressed by the noble Lord, Lord Ashley, the Government have accepted that the patients who, tragically, contracted HIV through NHS treatment were in a different position from others and we have made provision for them because of their special circumstances. As my noble friend Lord Campbell of Croy stated, those affected were all expected to die very shortly. In addition they were

[BARONESS CUMBERLEGE]
subjected to significant social problems, including ostracism. For instance, people were treated as lepers. They had their doors daubed with graffiti; they lost their jobs; and their children were not allowed to mix with other children at school. They were denied a normal married life.

In the case of the infected haemophilia patients, the problems of HIV were superimposed on the health, social and financial disadvantages they already suffered as the result of their hereditary haemophilia. I know that the noble Lord, Lord Ashley, is anxious that those patients with haemophilia who may have been infected with Hepatitis C should receive similar consideration to the HIV victims. But if an exception were to be made there would be others who would argue that they too were deserving. The noble Lord, Lord Ashley, and the noble Baroness, Lady Jay, may have forgotten that when payments were agreed for haemophilia patients with HIV, representations were subsequently made on behalf of blood transfusion recipients infected with HIV. After the settlement the campaign was intensified and payments were made to that group too.

Although patients receive the best treatment available, based on existing knowledge, it has to be recognised that not all medical interventions are risk free. Risks may be evident at the time of treatment or may be discovered later. If we were to offer payments for each such incident we would soon slip into a general no fault compensation scheme.

The noble Lord, Lord Addington, and the noble Baroness, Lady Jay, made a point of drawing a distinction between compensation and *ex gratia* payments. It does not really matter whether we call it compensation or *ex gratia* payments. The arguments against both are the same. Additionally, I stress that the majority of the payments made were not *ex gratia* since an undertaking had to be made not to take the matter to the courts.

Your Lordships will be aware that the Government are opposed to a no fault scheme. There are sound reasons for this. First, proof of causation is still need. It may be just as difficult to establish that the medical treatment has caused injury as it is to prove that someone has been negligent. It also has to be demonstrated that it was not a foreseeable and reasonable result of treatment It would be unfair to others in that those whose plight was the result of a medical accident could be compensated whereas those whose condition stemmed, for instance, from disease or birth would not. The costs of any such scheme would be substantial and would inevitably impact on the amounts available for patient care. Health care negligence is not considered to be fundamentally different from negligence in other walks of life where claims for compensation are resolved through the courts. In addition, the present system arguably has a deterrent effect on malpractice. No fault compensation might conceivably encourage doctors to be less cautious.

The experience of other countries which have tried to follow the no fault path has strengthened the Government's views. In New Zealand, whose system is most often quoted, several major problems have become apparent. The costs of the scheme have proved to be extremely high. Estimates of more than 1 per cent. of GDP have been made. In addition to a number of other practical difficulties, the scheme also effectively denies people access to the courts.

In Sweden a different scheme operates. The payments made are relatively small. Indeed, it was necessary for the authorities to make additional payments to those infected with HIV because of the inadequacy of the sums available through the no fault scheme.

I do not wish to minimise the impact of Hepatitis C on those who have been infected. For some it is a real tragedy, not only for themselves but for their families and friends. The Government have every sympathy for them. However, it has to be acknowledged that Hepatitis C is different from HIV. Many people infected with Hepatitis C may enjoy a long period without any symptoms appearing.

The noble Lord, Lord Ashley, presented figures on the natural history of Hepatitis C which were similar to those available to my department. However, I would put the figure for chronic hepatitis at 50 per cent., and 80 per cent. for those who do not recover fully after infection. Noble Lords will forgive me for repeating some of the estimates.

Fifty per cent. of sufferers may progress to chronic Hepatitis C with varying degrees of good and ill heath. Perhaps 20 per cent. of patients will develop cirrhosis, a progressive destruction of the liver that may take 20 to 30 years. The majority of those years will be trouble-free in terms of ill health and only a very small percentage will actually die of liver disease.

We readily acknowledge that each death is an individual tragedy for the family concerned. If we look specifically at haemophilia patients, the Haemophilia Society has stated in a press release launching its current campaign that over 40 people with haemophilia have died as a result of infection with Hepatitis C virus. It is important that we retain a clear sense of proportion and timescale. The figures quoted by the society relate to the five years between 1988 and 1993. I understand that, for example, in 1993 12 haemophilia patients died with the cause of death shown as liver disease. That was out of 126 haemophilia patients known to have died in that year. Of those 12, eight were also HIV positive. I seek in no way to minimise the tragedy but these are small numbers when weighed in the balance of the good that treatment has brought to many of these and countless other haemophilia patients.

My noble friend Lord Campbell of Croy asked about women haemophiliacs. I understand that virtually no women are haemophiliacs. There is a similar disease called von Willebrand's disease which affects both men and women, and some patients have contracted HIV and/or Hepatitis C.

I can assure the noble Lord, Lord Addington, that the Government remain very concerned about the position of people who have been infected with Hepatitis C Discussions are taking place between the department and the directors of the haemophilia centres about what needs to be done. We need to develop further good practice for the treatment of people with haemophilia who are also Hepatitis C positive and to ensure that they have ready access to treatment centres. The department is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus.

It is the Government's view that the most effective use of finite resources is to seek to improve the understanding, management and treatment of the condition. I know that that view is shared by the majority of clinicians in the field. Only in this way can the impact of the disease on individual patients and their families be effectively minimised.

4.6 p.m.

Lord Ashley of Stoke: My Lords, I am very grateful to those who have taken part in the debate. I echo the regret of my noble friend Lady Jay about the small number who have participated because we regard this as an important debate.

I am afraid that I must put the noble Lord, Lord Campbell of Croy, right. He said that I may not have known about what happened here seven years ago. In fact, I was one of the activists in another place on precisely this issue. I attended all of the meetings dealing with the campaign at that time although I was not a Member of this House then. I am more than happy to give way to the noble Lord.

Lord Campbell of Croy: My Lords, I am grateful to the noble Lord. We have plenty of time.

The noble Lord is under a misapprehension. I certainly knew of his activities at that time. I reminded your Lordships' House about what happened when I originally raised these matters because I realised that some noble Lords taking part in the debate were not here then. Of course the noble Lord and I spent many years in another place dealing with a number of subjects which arose in the disabled field. I knew that he was active in the other place at that time on this subject, but in the same way I did not know what exchanges took place and exactly how the subject was raised. The noble Lord can be at rest. I certainly knew that he was active at that time. I merely reminded your Lordships of what happened in this Chamber.

Lord Ashley of Stoke: My Lords, I am glad that we have clarified the issue. I not only knew but admired what was being done here because it was very helpful indeed. However, it is as well to set the record straight.

The noble Lord, Lord Addington, said that it may be necessary to set up another organisation. I would go along with that. If when the Minister changes her mind, as I am sure she will shortly, she does not want the McFarlane Trust to do the work but would prefer another organisation to undertake it, she has my agreement in advance. I hope that she will take note of that.

I agree with every word that my noble friend Lady Jay said, except that I believe that she should have used the word "shall" instead of "should". Apart from that one detail I agree with her 100 per cent.

I am afraid that it is not a great day for the Minister. I suspect that her brief was written before the debate and before people knew the essence of the debate. The essence was that we were not dealing with compensation, but much of the opening part of her speech dealt with the compensation issue, which is totally irrelevant. I am becoming boring on the subject, but we are not asking for compensation. We are asking for an extension of the *ex gratia* payment only for those people who are ill and for the relatives of those who have died. There is no question of asking for compensation in the established and accepted sense. I am sorry that the Minister spent so much time on that issue.

The Minister said that Hepatitis C is different from HIV. I explained in my speech how different it was. However, I also sought to emphasise the similarities. If a man is seriously ill from Hepatitis C, he is in the same position as someone seriously ill from HIV. (I am prepared to accept an intervention.) If a man dies from Hepatitis C, he is just as dead as someone who dies from HIV caused by contaminated blood. Admittedly, the social points about ostracism and so on are different. But the essence is illness and death. We are talking about the small minority who are ill and those who have died. I stated that five or six times in my speech. I admire the Minister very much; I am fond of her. But we must try to attain some understanding on the issue. We are talking about that small minority.

I must not continue. Other matters are to be debated. It has been a depressingly short debate. However, I promise the Minister this: I shall not let her down. I shall come back to the subject for further discussion in this House. Nevertheless, I thank her for her contribution. I beg leave to withdraw the Motion.

Motion for Papers, by leave, withdrawn.