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Westminster Hall

Tuesday 7 March 2000

[Mr. Michael J. Martin in the Chair]

Haemophiliacs

Motion made, and question proposed, That the sitting be now adjourned. [Mr. Kevin Hughes.]

10 am

Mr. Michael Mates (East Hampshire): I am delighted to have the chance to address you, Mr. Deputy Speaker, on this important subject. I have had a long wait to obtain such a debate. As I do not often appear on the health scene in the House, I should explain why I want to discuss haemophiliacs. When I became a Member of Parliament in 1974, my constituency contained Lord Mayor Treloar college, a school for physically disabled children. At the time, the college was the primary specialist treatment location for haemophiliacs in the south-east. I became involved with it as the tragedy of contaminated blood began. I saw the children there; 80 of them were infected by contaminated blood, and 50 of them, alas, are now dead. Since then, I have been involved in the matter for almost all of my time in Parliament.

Towards the end of the 1970s, I met the now chairman of the Haemophilia Society, Mr. Chris Hodgson. He is a constituent of mine, which is a further reason for my continuing interest and concern. GRO-A

GRO-A and I pay tribute to him for the work that he has done on behalf of all who suffer from this dreadful disease.

I want to draw attention to the cause of people with haemophilia who have been infected with hepatitis C through the use of contaminated blood products used in their national health service treatment. Those of us who have been campaigning for many years on behalf of such people hope to hear from the Government a new commitment to take action to help. People with haemophilia are a small but vulnerable patient group comprising no more than 5,000 people in the United Kingdom, 500 to 600 of whom live in Scotland. They suffer from a rare, lifelong genetic condition that is passed on through families and for which there is no cure. As a result of their genetic disorder, people with haemophilia lack essential clotting factors in their blood, which means that without treatment, painful and disabling internal bleeding occurs, affecting joints or organs. Modern treatment involves injection of the missing blood clotting factors to prevent this internal bleeding. From the 1970s, that treatment became available using clotting factor replacement products manufactured from human blood. Tragically, it was through that route that some 1,200 patients with haemophilia were infected with the HIV virus and more than 4,000 were infected with the hepatitis C virus in the 1970s and early 1980s through their national health service treatments.

Contaminated blood had been used to produce the treatment products, and the haemophilia population had paid a heavy price. In 1985 in England--and 1978

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in Scotland--procedures were introduced into the manufacturing process to eliminate blood-borne viruses. However, their introduction came too late for the majority of the patient group, who had been treated and were already infected. More than half of the people infected with HIV have now died--a total of more than 700 deaths. Of those infected with hepatitis C--a number of whom were co-infected with HIV--figures collected by the UK haemophilia doctors organisation show that some 113 have died through liver disease and liver cancer, both of which are related to the end stages of hepatitis C. However, because no official statistics have been published on the hepatitis C-infected haemophilia population, the number of hepatitis C-related deaths might be much higher.

The progress of hepatitis C is slower than that of HIV. It can take 20 to 30 years, but when it becomes active, it is extremely damaging. Hepatitis C attacks the liver. Within the hepatitis C-infected haemophilia population, many of whom have been infected by the virus for more than 20 years, the toll is becoming apparent. Current medical opinion is that up to 80 per cent. of people infected with hepatitis C will develop chronic liver disease; and that up to 25 per cent. might develop cirrhosis of the liver, which might progress to liver cancer.

I am keen to avoid, as far as possible, making party points. The saga has lasted through the Labour Administration of the 1970s and the successive Conservative Administrations of the 1980s and 1990s; now, the problem is

again in the hands of a Labour Government. I was astonished and moved recently to be told by a sufferer of the debilitating illness that no Minister, Labour or Conservative, has ever said sorry that such a thing could have happened in our national health service; there have been repeated expressions of sympathy for sufferers, but no one has felt able to say that they were sorry. I am told that just to hear those words from a Minister would be a great comfort, not only to sufferers but to the relatives of those who have died. I hope that the Minister will take that on board; all right-thinking people would warmly applaud him, were he to use those words.

Unfortunately, there is as yet no fully effective treatment for the virus. Progress is being made with combination therapy involving interferon and ribavirin, which was licensed last year, but it does not succeed for all. The treatment has been shown to clear the virus in 30 per cent. of cases. People with haemophilia might be less responsive to the treatment than the general population. The treatment often carries unpleasant and, for some, intolerable side effects. To compound the anxiety and distress suffered by the community, health authorities in many parts of the country are refusing to fund the combination therapy, thereby denying the only hope of a cure to those willing to undertake the onerous treatment. I hope that the Minister will address the matter immediately.

I wish to read one sentence from a letter from Baroness Hayman, then Under-Secretary of State for Health, dated 23 July, to the hon. Member for Birmingham, Sparkbrook and Small Heath (Mr. Godsiff). She writes:

With regard to the funding of treatment for people with haemophilia infected with hepatitis C, we have made it clear to Health Authorities that care is to be provided for all clinical conditions on the basis of clinical need and effectiveness.

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That could hardly be clearer. I have a further letter, dated 3 December 1999, from the Under-Secretary of State for Health, Lord Hunt of Kings Heath. He wrote to Lord Morris of Manchester, who continues to take an active interest in the matter, that

In the meantime, we will follow up cases where there are local difficulties and where, despite the clinical evidence of benefit, people with haemophilia and hepatitis C are not receiving the therapy.

That, too, could hardly be clearer.

I shall briefly quote a third letter, from the Secretary of State for Health. The last sentence reads:

In the meantime, we are following up all the cases where people with haemophilia and hepatitis C are not receiving this treatment, when prescribed by their doctors. Yet today--on 7 March--eight, three and two months after the letters that I have quoted were written, patients are still being denied the treatment on the ground of cost. West Hertfordshire, Sunderland and Avon are among the health authorities that say that they cannot afford to provide it, although in two recent and exceptional cases it has been allowed in Avon. Is not it a scandal that a Minister's promise is being openly defied by some health authorities? Will the Department stop wringing its hands over this important issue and ensure that it runs the authorities that it is supposed to control? The defiance is unacceptable.

As a last resort, a liver transplant is the only treatment, but it does not eliminate the virus and, in due course, the new liver becomes infected. I understand that there are no official figures, but at least 20 sufferers from hepatitis C have had liver transplants and several have had more than one. The cost of a drug surely bears no comparison with the cost of repeated liver transplants. Transplants postpone but do not permanently stop the progress of the virus. Waiting lists and delays are common for liver transplants. Those living with hepatitis C therefore endure great uncertainty. Doctors are unable to predict how the virus will affect an individual's health and how soon or seriously he or she may become ill. That creates great stress and anxiety, especially for people with family responsibilities.

I was astounded to find that there are no counselling facilities for people with hepatitis C or for the dependants and families of those who have died from the infection. The Government should at least offer that, and ensure that health authorities provide for those unfortunate people. Research by the Haemophilia Society illustrates the disastrous impact of the infection on the lives of families who were already fighting to overcome a lifelong health problem. Many have had to do less work or give it up because of the effects of the virus, which has led to hardship and loss of income. Serious problems have been caused for people wanting mortgages or life insurance, once they have been diagnosed with hepatitis C. Fear of passing on the virus within families has created terrible stress on relationships between parents and children and husbands and wives. Social stigma is another result and there is evidence of people being shunned by neighbours, friends and colleagues because of the virus.

All this has come about because contaminated products were used to treat people within our national health service. The infection of people with haemophilia

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with these deadly viruses has been described as one of the worst treatment disasters in the history of the NHS and even now there is little peace of mind for the patient group as there is also a threat of new variant Creutzfeldt-Jakob disease. Experts are agreed that there is no way of guaranteeing that blood products still used for the treatment of haemophilia are free of CJD infection. The Department of Health describes the risk as theoretical, but how must it feel for the patient or the parent of a young patient to know that the treatment relied on daily might carry CJD?

Those of us campaigning to highlight the plight of this patient group want action from the Government. The previous Government accepted that they had a moral responsibility to help those who had been infected with HIV through NHS treatment and, with all-party support in 1987, the Government established a financial assistance scheme. The Macfarlane trust was set up in 1998 to administer it and some £90 million has been made available in across-the-board payments and hardship grants. However, nothing has been done for those affected at the same time in exactly the same way with hepatitis C. The Government must correct that injustice.

In July 1998 the then Secretary of State for Health, the right hon. Member for Holborn and St. Pancras (Mr. Dobson), turned down the Haemophilia Society's appeal. His justification was that the harm done was inadvertent and that therefore no financial assistance was due. The same point could have been made about HIV infection. There, too the harm was inadvertent, but the previous Government accepted that they had a moral responsibility to help. We ask the Government urgently to reconsider their decision.

This is not a debate about medical negligence because the previous Government made financial help available on an ex gratia basis without any admission of liability. The same step should, in conscience, be taken for hepatitis C. In contrast with 1987, the mechanism exists, in the shape of the Macfarlane trust, to administer the hardship fund for those who suffer the consequences of receiving contaminated blood products. It would be straightforward for the Government to extend the remit of the Macfarlane trust to enable it to help for those who are affected by HIV and hepatitis C. The trust has earned the respect of all concerned by the way in which it has acted as the Government's agent for HIV infection. There would be no need to reinvent that particular wheel. It would require only a simple amendment to the trust deed and the funding to allow the Macfarlane trust to continue to act efficiently. I am sure that that would command all-party support and be welcomed as a fair and just conclusion to the inequity.

It is a shocking irony, given the family inheritance of haemophilia, that a dividing line must be drawn between brothers and cousins in the same family who have been infected by contaminated blood products at the same time. Those who were infected with HIV and hepatitis C viruses together are entitled to financial help, but that is not necessarily the case for those who contracted hepatitis C alone. For some, the infection--through no fault of their own--is a life sentence; for others, it is a death sentence. Can we tolerate such a lottery in the 21st century? I understand that other colleagues want to talk about the additional problem of haemophiliacs who have been doubly infected by HIV and hepatitis C in greater detail.

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The issues are too important to let rest. The Haemophilia Society has called for a public inquiry so that all the facts about how the infection occurred and its impact on those who were infected are brought into the open. That is the least that is due to haemophiliacs who will live with the consequences of contracting HIV and hepatitis C infections from contaminated blood for the rest of their lives. Most important, in the interests of protecting public health, we need a full inquiry to ensure that lessons are learned so that such tragedies do not occur in future.

Governments in other countries have not shirked their responsibilities. In Canada, a full Government investigation was held and, in Ireland, the Government established a tribunal inquiry, which is authorising compensation payments. Closer to home, in September, the Scottish Minister for Health and Community Care, Susan Deacon, initiated an inquiry into the infection of Scottish haemophilia patients. Ministers have taken the line that Scottish cases are different. The detail may be different--heat treatment for blood products happened later in Scotland and there is the question of what information was given to Scottish patients--but the principle is the same. I trust that the Minister will agree that it would be unacceptable for a devolved Scottish Parliament to

compensate victims of hepatitis C contamination in Scotland if victims in England and Wales are not compensated. That would be another unexpected consequence of the Government's hasty devolution legislation, and it would turn English and Welsh patients into second-class citizens.

I know that Ministers are sympathetic to the cause, and I hope that what I am about to say will not embarrass them too much. I have before me an early-day motion, tabled in 1995, which called on the Government to give similar financial assistance to those infected with hepatitis C as was given to those infected with HIV. It was signed by the Minister and his boss, the Secretary of State. I do not believe that they have changed their principles in four years, so their duty must be clear. I know that there are constraints in government that are not there in opposition. Nevertheless, this is a wonderful opportunity for them to be consistent in their demands for fair play for those victims.

It would do much for those who cynically believe that the Government do not care, if a reply were made to the appeal delivered to No. 10 Downing street on 23 November last year by a cross-party delegation led by Lord Morris, in which several hon. Members present today and I took part. I was saddened to hear yesterday that the appeal has not even been acknowledged, which would cost only the price of a postage stamp.

Justice requires that the Government should set up an independent inquiry into the matter, as has been done in Scotland. There, evidence has been taken from the blood transfusion service, doctors and patients with haemophilia and hepatitis C, which is being investigated by the Scottish Health and Community Care Committee. Surely, we should demand no less for victims who live in England. I should not like to have to hear the Minister justify the fact that, although the findings of the Scottish inquiry were being implemented, he was not prepared to do the same south of the border. I urge the Minister to give a commitment today to have the whole sorry affair independently examined, not just because compensation might be awarded as a result,

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although the justice of that would seem to be unquestionable, but to ensure that such an unfortunate and tragic accident can never happen again and that never again will national health service patients be damaged by such a terrible mistake.

10.21 am

Mr. Bob Blizzard (Waveney): I was one of those Members of Parliament who accompanied 15 representatives of the Haemophilia Society to No. 10 Downing street last November when we laid 113 white lilies on the steps, one for every person in the United Kingdom who has died from hepatitis C, contracted through contaminated blood--a very moving occasion it was too.

I joined that delegation because of one of my constituents, Mr. [GRO-A] of [GRO-A] Mr. [GRO-A] suffered from mild haemophilia and, many years ago, he was given a clotting agent after two wisdom teeth were extracted. That was when his troubles began because the clotting agent was derived from donated blood, which was subsequently discovered to have come from a batch that was unscreened. That batch of blood was contaminated, so my constituent contracted hepatitis C. Mr. [GRO-A] is now 62 years old and he is a very different person from the person he used to be. Many years of suffering as a result of that damaging incident have taken their toll. Before the incident, he had a good job as a helicopter control officer on an offshore rig, but his liver was seriously damaged and his whole system was poisoned. That affected his brain so that he became confused and disoriented and, no doubt, he was also affected by the worry and trauma.

First, drug treatments, with very unpleasant side effects, were tried, but they failed to work. Eventually, it was decided that he needed a liver transplant to survive at all. He had his first liver transplant in December 1995, but unfortunately it was unsuccessful, so he underwent a second liver transplant operation in August 1996. One such operation is difficult, but two is a trial indeed.

I first discovered his case in 1996 while Mr. [GRO-A] was at Addenbrooke's, which is about 90 miles from [GRO-A] At that time, I met Mrs. [GRO-A] who was ill herself from chronic worry about her husband's ill health and the way in which he had contracted hepatitis C, as well as from worry about how they would make ends meet because they incurred considerable costs in getting to and from Addenbrooke's. In addition, their family life was greatly disrupted. As a result of what had happened to [GRO-A] that family suffered not only inconvenience but financial penalties. Not only did he suffer the financial loss of two thirds of his income when he had to give up his job, but his pension was affected. He had been looking forward to retirement with a good pension.

Mr. [GRO-A] does not blame the national health service or the medical profession for what has happened to him. He realises that it was no one's fault. He knows that it was unfortunate that those blood products were not tested at the time. However, he feels that it is wrong that he should suffer financially for so many years--he will continue to suffer financially into his retirement--for something for which he was not responsible.

The nub of the argument is that people such as Mr. [GRO-A] have a moral case. He is not asking for a huge litigation-style compensation payment that

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acknowledges fault. He wants people in a similar position to receive some modest support that will enable them to receive the regular treatment that they need, and that will help with the cost of travelling to hospital and of the prescriptions that they often need.

The question is simple. Cannot the Government perform an act of good will? Despite the fact that they have no legal liability, cannot they widen the remit of the Macfarlane trust to cover people suffering from hepatitis C? To do so would be medically and morally justified. I suspect that the Government have taken the same position as the previous Government because they have been given the same legal advice. When two Governments take the same position, one usually suspects that that is the reason.

This is a time for compassion. We want compassion to find a way through the legal tangle, so that people such as GRO-A can receive the help that they deserve.

10.27 am

Mr. Mike Hancock (Portsmouth, South): I congratulate the hon. Member for East Hampshire (Mr. Mates) on having the good fortune to win the debate lottery. I thank him also for the generous way in which he put his case. He did not attempt to score political points. He put the case that successive Governments have been involved. However, for most of those who listened to the hon. Gentleman's speech on radio or television, the question of reasonableness will far outweigh any legal ramifications or responsibilities that the present or previous Governments might have faced.

The British people who listened to the hon. Gentleman's speech will have had an insight into what those people affected and their families have faced. They would say that now is the time--albeit, long overdue--for the Government to recognise that the nation has a responsibility to them. That wrong should be righted sooner rather than later. An inquiry cannot possibly be justified, laudable though the sentiment is, because all the evidence is available. People went for treatment and, through no fault of their own, left hospital in a far worse state. The way in which the treatment was given, and the reasons why contamination took place are now irrelevant. Most of those who receive national health service treatment expect to benefit from it, not to see their lives and those of their families and loved ones systematically destroyed.

We heard of one such incident from the hon. Member for Waveney (Mr. Blizzard). Two friends of mine suffered from this. One, a journalist living in this country, is now dead. Sadly, he died not long after he was infected; he contracted hepatitis C and, as a result, other infections that subsequently killed him. I am sure that medically it could be argued that his haemophilia might have led to his death at that stage anyway, but his family are convinced that his death in his early forties was due to the infection via contaminated products.

Another friend, a French politician whom I met while I was leader of Hampshire county council, also suffers from haemophilia and he was infected with hepatitis C in France. The difference is that he is still alive and has received substantial compensation for what happened

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to him. At no stage was there any doubt about the sort of treatment that he would receive. He did not suffer from the lottery whereby the part of the country in which he lived determined whether he received the right treatment. He and his family also received substantial sums in compensation. Nothing can ever truly compensate individuals and their families, and, sadly, for many of them any compensation would be too late. As we have heard, people and young children have died. Those lives have been needlessly lost. The nation owes sufferers some justice today. It would be wicked to allow the situation to continue. The wrong would simply be compounded. That cannot be right.

I am grateful to the Haemophilia Society for its latest briefing, which lists eight of the major problems faced by sufferers and their families. The hon. Member for East Hampshire touched on a few of those, but it is worth mentioning them again, and perhaps the Minister will let us have his ideas on possible remedies. There is the difficulty in obtaining life assurance, the reduced income through having to cut working hours or give up work altogether, and the increased costs due to special dietary requirements and medicine charges. The education of many young people with haemophilia and hepatitis C has been adversely affected and job and life opportunities have been lost. People suffer from discrimination and ostracism at work or school and in society in general. That maybe difficult to believe but one need only ask some of the sufferers and their families. They will give chapter and verse of many such incidents. They fear for their future health and leaving their dependants without financial support. With young children and heavy commitments, and an illness that has already resulted in the early deaths of many others, how does one contemplate the future financial support of a family without life insurance?

There is a lack of support and counselling services for hepatitis C sufferers. How can it be that after 20 years, individuals and their families are still suffering from such problems. If any of us, heaven forbid, were to witness a fatal accident outside this building, we would insist on receiving trauma counselling and advice. Why do sufferers not receive what most of us now assume is available for everyone. Why are those people, through no fault of

their own, unable to receive life insurance, something basic that almost everyone takes for granted? Why can we plan for our children's lives after we have gone, while they are nagged with constant worries about the future of their families? It is enough that they have to worry about their families, seeing them suffer while they are alive, yet they also know that their families will have to fight the issue after they have gone.

Other hon. Members will have an opportunity to go into further detail about effects that such individuals have had to take in their stride. The numbers are not large, but we are talking about human beings with a significant problem. As the hon. Member for East Hampshire said, the Minister and his Secretary of State signed an early-day motion. With hindsight one could say that perhaps neither of them expected to be confronted with the same difficulties or legal advice as their predecessors were. When they signed it, perhaps they thought that changes would be easy to make when they came to office. We wish that that had been the case.

Whatever the difficulties, they cannot be as bad as those that the individuals face. They and their families are crying out for justice. Why have successive

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Governments simply not got to grips with the problem and given those people the justice that they deserve? Those of us who have had the privilege of meeting them and their families have been told that they do not want huge financial payments, although I believe that they should. They want continuity of care so that there is no uncertainty about which drugs they can have, no matter where they live. Why can they not be assured today that there will be equal care, with no drugs or treatments denied and no opportunity to give them a better life not taken?

Why can we not make ex gratia payments available to them as we did to those infected with HIV? The mechanism is there. There is no encumbrance on the Government to do the right thing. The legal opinion may be that a minefield of other issues will be created, but nothing could be worse than what those people and their families have lived with for nearly two decades. It would be a disgrace if the matter were still unresolved a year from now. At the end of the debate, I hope that the Minister will give everyone concerned the hope of seeing long-overdue justice in a matter of months. Anything short of that would be a disgrace to the nation, let alone our political system.

10.38 am

Mr. Roger Godsiff (Birmingham, Sparkbrook and Small Heath): I want to take a couple of minutes to add my support to what has been said. I apologise to my hon. Friend the Member for East Hampshire (Mr. Mates) for being late and missing the start of his speech.

Like all Members of Parliament, I am frequently brought cases and causes, and I have never come across a greater injustice to a group of people during my eight years in the House. Haemophiliacs have a diminished life style. The fault is not their own; the disease that they have no choice but to live with is inherited. The 5,000 people who suffer from haemophilia put their faith in the national health service for blood transfusions. Sadly, 1,200 were given blood infected with hepatitis C, and, of those, I regret that 700 have already died.

I realise that the Department of Health sympathises with those people, just as it did with people with HIV. I pay tribute to the former Prime Minister, who insisted that the problem of HIV be dealt with. That was done through the Macfarlane trust, into which £98 million was paid, which was subsequently topped up with an additional £3 million. At the time, I spoke to the then Secretary of State, who said that the advice from his Department was, "Don't do it. You will set a precedent. Don't give way." However, the previous Prime Minister felt a moral obligation to deal with the people involved, and insisted that action be taken, and the then Secretary of State created the Macfarlane trust. I pay tribute to him for doing so, because it was the correct decision to deal with a group of people who suffered from a life-threatening disease that would almost certainly result--

Sir Geoffrey Johnson Smith (Wealden): I confirm what the hon. Gentleman says, having been part of the delegation that initiated discussions with the then Secretary of State and having assured him that there would be no question of people taking advantage of an

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ex gratia payment paid into a charitable trust. That assurance has been honoured, and I am surprised that such a procedure cannot be followed again.

Mr. Godsiff : As my right hon. Friend says, HIV sufferers have honoured that agreement. Those who, through no fault of their own, have been given contaminated blood ask not to become mega rich through massive legal claims but merely to have, especially, for their families, the same sort of provision. As hon. Members have said, once a haemophiliac contracts hepatitis C he knows that he will die sooner rather than later. Those people's anxiety relates not to

their anger about having contracted the infection but to their hope for provision to be made for their families when they die.

I am sure that the Minister will show copious sympathy for those people. I do not want to remind him of the fact that he and the Secretary of State signed an early-day motion calling for justice for them. I believe that the Minister would like to help them, but I know the bureaucratic response that the Department will give, because I received it in 1998 from the then Secretary of State, the right hon. Member for Holborn and St. Pancras (Mr. Dobson), who said:

The Government has proceeded on the basis that compensation or other financial help to particular patients or groups of patients is only paid out where the NHS or individuals working in it have been at fault. The needs of people whose condition results from inadvertent harm is met from benefits available to the population in general. I am sorry to have to tell you that after considering all aspects of this matter we have decided that we should not make an exception to the general rule in the case of haemophiliacs infected with hepatitis C.

He went on to say:

You have also argued that as the Government provides financial help to haemophiliacs infected with HIV this scheme should be extended to cover people with hepatitis C,

but that the Government take the view that those circumstances were different.

That was in 1998. The then Secretary of State is now entering a new life. It will be interesting to see what position he takes as the potential new mayor of London when addressing the needs of haemophiliacs. It will be interesting to see what he has to say to them and what his feelings are now on the subject.

This is a matter of justice. Haemophiliacs are not asking for the earth; they are not asking for revenge; they are not asking for mega bucks; they want only to

be treated in the same way as the HIV sufferers who were infected with contaminated blood. They have done nothing wrong. They put their faith in the national health service and have no option but to continue to put their faith in it. They do not wish to have the national health service held up to ridicule. They want only justice and I hope that, when the Minister responds, he can offer that to them.

10.45 am

Dr. Peter Brand (Isle of Wight): I congratulate the hon. Member for East Hampshire (Mr. Mates) on securing this debate.

The infection of haemophiliacs with hepatitis C is something I feel strongly about since, in my medical career, I may well have been responsible for some of

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them contracting this dreadful disease. When I first qualified, the treatment of haemophiliacs was largely conservative, with the use of ice packs, immobility and treatment to prevent arthritis and joint damage, which are so often a consequence of such a difficult disease. There was then a positive change in medical policy with the availability of factor 8 and other blood products to treat even minor bleeds. I am not sure whether we adequately evaluated the risks of such treatment in the late 1970s and the early 1980s.

The hon. Member for Birmingham, Sparkbrook and Small Heath (Mr. Godsiff) rightly pointed out that we are dealing with blameless victims. Those people took medical advice; they put their trust in government policy in the treatment of their disease expecting to lead a more active life and become less of a burden on the state than if they had accepted the conservative treatment that might have resulted in disabilities.

The hon. Member for Waveney (Mr. Blizzard) made a generous speech in which he spoke of a no-fault situation. My hon. Friend the Member for Portsmouth, South (Mr. Hancock) felt there was no need for an inquiry. Clearly, there is no need for an inquiry if the Government accept responsibility for those who contracted hepatitis C as a result of government policy on the treatment of haemophiliacs. The mechanisms are there to help those people in the plight that has been so well described by right hon. and hon. Members.

If the Government do not accept responsibility, the only alternative is to call for a public inquiry, because I am not clear how long the Government were aware

of the risk of using potentially contaminated products--especially where they were imported-- or how long a delay there was in the identification of that risk before those products were properly treated. The Government must either accept that they have a moral as well as a legal responsibility towards those people and use the sensible mechanisms available to them through the Macfarlane trust, or accept responsibility for making all the facts clear about the change between the use of potentially infected products and the heated products. They do not have an alternative.

In the meantime, it is vital that the Government do more than write letters to right hon. and hon. Members saying that treatment and support should be available throughout the country. It should be an instruction. It is not acceptable for people to be treated according to their postcode, nor is it a matter for the National Institute for Clinical Excellence. The facts about the treatment are well established and I should not want further to overburden NICE. Apparently it can cope only with 30 investigations a year, so it would be a long time before it came up with any answers.

Sadly, the liability to support victims of therapeutically acquired hepatitis C is limited. They are dying slowly and, in some cases, quickly. We are not asking the Government for an open-ended commitment that cannot be evaluated. We know how many people are affected and we can evaluate what support they might need. It behoves the Government of a civilised country to look at their responsibility and admit that they have a role. They should then cost it, evaluate it,

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seek the support of the House, which I am sure will be overwhelming, and do something for that so far ignored group of people.

10.51 a.m.

Mr. Philip Hammond (Runnymede and Weybridge): I congratulate my hon. Friend the Member for East Hampshire (Mr. Mates) on securing this Adjournment debate. The hon. Member for Portsmouth, South (Mr. Hancock) may have been doing him an injustice by saying that he had been fortunate in the lottery. The first debate on Tuesday mornings is selected by Madam Speaker on the merits of the subject and I am delighted that she chose the subject that we are discussing. No one would doubt that there is overwhelming sympathy for haemophiliacs. Such people are already stricken with a disabling condition and over the past 20 or so years the great majority have been stricken

again either by HIV or by hepatitis C or, in all too many cases, by both. We share an instinctive horror at the thought that the very process of providing medical treatment can itself be harmful, and most would readily acknowledge that that is one of the worst treatment disasters in the national health service history.

I have a personal interest in the subject because, many years ago, fresh from university, my first job was in a company that was involved in the importation and sale to the NHS of anti-haemophilic factors. Although I was a junior and insignificant member of the team, I knew eminent doctors, scientists and pharmacists who were undertaking such work when there was great excitement about the possibility of producing products artificially that would eliminate the risk in their manufacture from national blood products. At the time, the risks and conditions of HIV and hepatitis C were unknown and the fears that we are now experiencing were not felt.

The hon. Member for Isle of Wight (Dr. Brand) asked whether sufficient investigation had taken place before the use of anti-haemophilic factors within the NHS. He did not acknowledge the significant improvement in the quality of life for those who had previously been encouraged to adopt immobility as a routine response to their disease. With the benefit of hindsight we can see that something went terribly wrong, but at the time--as I remember from having been on the sidelines--it was seen as a great victory and advance in the treatment of people unfortunate enough to have the condition.

My hon. Friend the Member for East Hampshire said that no one in the Government has ever said sorry for what happened to haemophiliacs. If that is the case, it is astonishing. From my observation of the scientists and doctors involved, whom I knew at the time and with whom I have stayed in touch over the years, I know that they were good people who believed that they were helping those patients. Later, with the benefit of hindsight, they realised that what they had been doing had systematically, albeit inadvertently, poisoned those people. That discovery has been a shattering blow to many of them. They are truly sorry for what has happened, although they genuinely did not realise the consequences at the time.

My hon. Friend made the case for compensation of the people affected. He said that when the Minister was

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in opposition, he had signed an early-day motion calling for that. I shall not make party political points because it is clear that a groundswell of sympathy for them exists across the political divide. However, both the previous and present Administration came to the conclusion, after careful review, that the principle that no-fault compensation should not be paid where there has been no negligence must remain as a general rule in a national health service that delivers health care free at the point of need.

There are significant problems with a no-fault compensation system. Causality would still need to be established and it may inhibit clinical practice, which is based on the best current knowledge at any given time, and may blur the line between negligence and innocent action, leading to a less accountable culture in medicine. Last but not least, it would involve a cost to the budget. It has been said many times that any compensation should be paid from a contingency reserve, but if no-fault compensation were accepted for medical accidents in general, beyond the specific matter of haemophiliacs with hepatitis C, there would be significant budgetary implications that could not be ignored.

The main argument advanced for compensation for this group is the unusual position of haemophiliacs infected with HIV. They were treated as a special case because it was felt that HIV was a unique condition in terms of its high mortality rate and the tremendous stigma attaching, certainly in the early days, to the disease.

Sir Geoffrey Johnson Smith : On that point, an assurance was given that if money were paid into the Macfarlane trust, there would be no question of legal action being taken and that has been honoured.

Mr. Hammond : I thank my right hon. Friend for that. It would be a great shame if an act of good will towards a suffering group of people who have a terrible disease became the benchmark by which other groups who have suffered as a result of medical accidents felt that they had been unjustly treated. I acknowledge the problem of where, in the spectrum of medical accidents, one should draw the line, but I readily understand the apparent injustice of two haemophiliacs who had acquired similar viral diseases from transfusions of contaminated blood products being treated differently.

The general principle should be to resist no-fault compensation for medical accidents in the NHS. That was the previous Government's conclusion, and it has also been this Government's conclusion, unless the Minister is about to announce a major change today. However, I shall qualify what I have said in two specific ways. First, it is, of course, relevant only where there is no negligence. If negligence were established, for example where information--either on the risk of infection or on the seriousness of the consequences of infection--that might reasonably have been used in decisions to change the treatment of at least some patients had been available was withheld, that would be a different matter. If it were clear that such negligence had occurred, the Government would have to move swiftly, without requiring individuals to enter into protracted legal action.

In the light of the inquiry that has been instituted in Scotland, is the Minister satisfied that conditions in Scotland are different from those in England and Wales?

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Does he think that, to confirm the absence of negligence, it was necessary to accede to the request for an inquiry? That is a separate issue from the question of whether compensation should be paid in cases where there has been no negligence.

It is timely, in the current climate of concern about new variant CJD, that we should be discussing this issue. Is the Minister satisfied that all the lessons from the experience of the haemophilia, HIV and hepatitis C issues have been learned, even if there is no evidence of negligence in his Department? Has he identified and eliminated any systemic or bureaucratic failures in the Department of Health or the national health service? All will agree that in 20 years' time we must not be debating the case of people who have been contaminated by new variant CJD in the course of medical treatment administered in the early years of the millennium.

Secondly, there is a strong case for dealing with all medical accidents--especially those involving identifiable groups, rather than just one-off cases--on their merits. We should ensure that the response is appropriate and does not always, or only, take the form of financial compensation; it could be the provision of effective treatment and support. Although I agree, reluctantly, that automatic no-fault compensation is not the right answer for the national health service, I urge the Government to examine the mechanisms for dealing with particular hardship in individual medical accident cases, not just as it affects haemophiliacs but across the spectrum--especially, as the hon. Member for Waveney (Mr. Blizzard) said, where hardship has resulted from treatment to alleviate the condition.

The former Secretary of State, the right hon. Member for Holborn and St. Pancras (Mr. Dobson), rejected the idea of special payments on 28 July 1998. He went on to say:

The needs of people whose condition results from inadvertent harm are met from benefits available to the population in general.--[Official Report, 28 July 1998; Vol. 317, c.179 WA.] Most people would agree, on a moment's reflection, that that is a rather harsh judgment and that people suffering particular hardship, as a result of medical accidents, are not always properly catered for by the general benefits system. I urge the Minister to consider the possibility of having a middle way that, although falling short of no-fault compensation for medical accidents, goes beyond what the general benefit system provides to the

public at large and offers proper support to those who have suffered from medical accidents that occur within the national health service.

Many of the problems that face haemophiliacs with hepatitis C also face the other 250,000 to 500,000 hepatitis C sufferers. That range is broad because nobody knows how many people out there in the community may carry the disease undiagnosed. Hepatitis C has been described as the real millennium bug and a ticking time bomb, because hundreds of thousands of people in this country may carry the disease without being aware of it. Some medical authorities have suggested that it has the potential to be a greater killer in the long term than AIDS. We need to consider the regime of treatment and support that is in place to deal with the disease generally, as well as in the particular case of people who have acquired it through contaminated blood products.

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My hon. Friend the Member for East Hampshire mentioned the apparent problem of transmitting the Government's intentions down to health authority level. The mechanism that the Government have used for that is the national service framework, which creates a clear structure and definition of what is to be expected from the NHS in a given case for a given condition. There is no national service framework for hepatitis C. Can the Minister tell us what strategy his Department has for co-ordinating prevention, diagnosis, treatment, care and support in cases of hepatitis C, to ensure that we have a national approach to this major problem?

As other hon. Members have said, standards of treatment for hepatitis C across the United Kingdom are variable. The interferon ribavirin combination therapy is denied to patients in many health authority areas because of funding problems. The hon. Member for Isle of Wight said that that therapy should not be referred to NICE for a report. Does the Minister concur with the hon. Gentleman's analysis, or will the Government seek to refer that treatment to NICE for a report? If there is to be no compensation for people affected by medical accidents, the least that we need do to restore confidence in national health service treatment is to ensure that the best corrective or palliative treatment is available.

All hepatitis C sufferers are entitled to ask what the Government are doing to control the disease and to support those who suffer from it. This matter was debated in the other place, where the noble Lord Winston, whose name might not normally have come to my attention but who has recently been prominent in our health debates, said:

although the Government came to power with a promise to abolish the internal market, it is a lottery as to whether these patients are treated by the NHS.-- [Official Report, House of Lords, 5 June 1998; Vol. 590, c. 673.] He went on to put, more eloquently than I could, the case for additional support for haemophiliac patients with hepatitis C.

Faced with the tragedy of a relatively small group of people suffering from a chronic and in many cases grave illness as a direct result of NHS treatment, the instinct or the knee-jerk reaction of all hon. Members would be to compensate. Ministers in the previous Government wrestled with their consciences over the question, and balanced the instinct to compensate with their wider responsibilities, and with the principle that compensation is usually paid only when negligence has been evident. It is impossible not to feel sympathy with the agonising plight of haemophiliac victims of hepatitis C, but the decision not to venture into the realms of general no-fault compensation is the right one, albeit a difficult one to make in the circumstances.

Mr. Mates : My hon. Friend has been talking for some minutes about a general principle with which few hon. Members would argue. We are discussing a specific problem, closely related to another which was treated by the Government--rightly in my view and that of my hon. Friend--as so exceptional that ex gratia payments should be made, despite its being no one's fault. I do not want to progress from the particular to the general, just

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from one area of the particular to another similar instance affecting people with the same genetic disease, haemophilia. People find it incredible that some should be compensated and some should not. We want to remove the lottery aspect of the matter.

Mr. Hammond : I understand my hon. Friend's eloquently put view, but the problem is where to draw the line when we begin to compensate for the effects of medical accidents. I would prefer cases to be considered individually, and would also like a review of the mechanisms for dealing with hardship arising from medical accidents.

It must be right, in any case, for the NHS to provide every available treatment for people whose condition has been exacerbated by NHS treatment and to provide appropriate support and counselling. I expect that all hon. Members would advocate that as a general principle. It is not inconsistent with that general principle that the Minister should tell health authorities to give the highest priority to treating hepatitis C haemophiliacs. What practical steps is the Department of Health taking, and what practical guidance has the Minister given to health authorities, to support this defined and unfortunate group of patients and ensure that treatment is properly available throughout the country? It is not acceptable for any patient to have to wait months or years to see a hepatologist, especially in the circumstances that we have heard about this morning.

I reluctantly support the conclusion reached by the previous and present Governments that no-fault compensation must generally be resisted in the national health service--I am sorry to disappoint my hon. Friend the Member for East Hampshire by taking that view--but I hope that the Minister will reassure us, and, more importantly, the thousands of victims of this terrible tragedy, by promising to examine the mechanisms for dealing with cases of hardship arising from medical accidents and by announcing improvements in access to treatment and counselling for the people affected by the accident that we are considering today. I hope that there will also be a step change in the pace of the battle against the spread of hepatitis C.

11.13 am

The Minister of State, Department of Health (Mr. John Denham) : I congratulate the hon. Member for East Hampshire (Mr. Mates) on raising this matter, and on doing it so effectively. There is much support and sympathy in and out of Parliament for the people with haemophilia who received infected blood products before technology could remove the infection. In the time available I hope to deal with many of the issues raised in the debate and, although I will not be able to satisfy hon. Members on all points, to show that we are more than sympathetic and have practical action in hand.

We want the people concerned to be increasingly well cared for in the NHS, to be supported in their communities and to be better informed about how to look after their health. I recognise the role of the Haemophilia Society, which has led to a forceful and moving campaign for special recognition for people with haemophilia and hepatitis C. We have worked

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closely with the organisation and will continue to do so. As has been said, people with haemophilia were more severely affected before blood products were developed. Apart from the distress of the condition, they faced deformed joints and general incapacity, and children suffering from the disease typically attended special schools.

Blood products were developed from the late 1960s onwards and were a huge step forward. They were easy to use and people could treat themselves at home rather than go to hospital. They were also transportable, and people could take them with them if they went away. They improved the quality of people's lives at the time, and sufferers' longevity increased to nearly that of the general population. The ill effects of haemophilia were beginning to recede. I understand that the existence of a different sort of hepatitis virus was known in the early days of blood product manufacture. It did not have a specific name until 1989 and there was no test for it until the late 1980s. Experts advised that there was no reliable test until the early 1990s.

It was suggested that nobody had said sorry, but I was not aware that that was the case. I wonder how anybody, including Ministers, could not be sorry about the sequence of events set out today. But, as has been generally agreed, it would be wrong to confuse regret with fault or blame. If I have time, I shall trace some of the history of how blood products were treated, but I would rather concentrate initially on the substantive issues raised concerning the action that we should now take.

The outlook for the treatment of hepatitis C has progressed. The first treatment, an anti-viral therapy, became available in 1995. Work was also beginning then on the combination of interferon with other anti-viral agents such as ribavirin. I understand that the success rate of the first therapy was modest and that about 20 per cent. of patients cleared the virus. However, the second generation therapy using interferon with ribavirin has been shown to be more successful.

Interferon with ribavirin--more easily referred to as the combination therapy--was licensed last summer. Hon. Members have asked about NICE. We have referred combination therapy to NICE, which is assessing it as a matter of urgency. It has recently written to the interested organisations to seek their input, and we look forward to receiving its recommendations in a few months' time. As has been said elsewhere, NICE is a key mechanism for giving authoritative guidance to the national health service on the clinical and cost effectiveness of a range of treatments. It will be a key tool in tackling the unacceptable variations of access to treatment and care that currently apply in respect of a number of different procedures and treatments.

Dr. Brand : May we have an assurance that, if the matter has been referred to NICE, it will not invoke the affordability criteria and the decision will be taken by Ministers?

Mr. Denham : As it does on all other procedures, NICE will consider the clinical and cost effectiveness of the treatment. That is set out in the rules according to which NICE operates. The fact that NICE is considering combination therapy is not a barrier to its

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prescription and provision. In response to concerns expressed by a number of hon. Members, the Government have followed up with a number of health authorities when a moratorium was imposed or about to be imposed. Referral to NICE is a key move forward in resolving combination therapy treatment issues. I understand that liver transplantation following hepatitis C, which was mentioned by the hon. Member for East Hampshire, will be taken into account by NICE as part of the process of considering the provision of combination therapy.

As I have mentioned, we place great value on the work of the Haemophilia Society, with which we shall continue to work. A key issue is the campaign that the society has run with others for a special payment scheme for haemophilia and hepatitis C infections. Several right hon. and hon. Members, including myself, signed an early-day motion in 1995 requesting that financial assistance be considered. That causes me no embarrassment because, especially in opposition, hon. Members often raise issues of concern so as to put them at the top of the agenda and require Ministers to consider them. Indeed, when the Government took office, meetings were held with the Haemophilia Society and the issue was carefully considered. Every consideration was given to the possibility of a special payment scheme for those with haemophilia and hepatitis C. During that time, we continued to work with the society on several other issues, such as our requirement that health authorities should provide recombinant synthetic factor 8 to children under 16 with haemophilia and new patients. We concluded that haemophiliacs infected with hepatitis C should not receive special payments, and some of the arguments for that were rehearsed earlier in the debate. As my right hon. Friend the then Secretary of State informed the House,

Government policy is that compensation or other financial help to particular patients or groups of patients is paid out only where the NHS or individuals working in it have been at fault. The needs of people whose condition results from inadvertent harm is met from benefits available to the population in

general.--[Official Report, 28 July 1998; Vol. 317, c. 179WA.] On that basis, we decided not to make an exception to the general rule in the case of haemophiliacs infected with hepatitis C.

Mr. Hammond : Does that mean that the Minister is quite certain that all the necessary investigations have already taken place to rule out the possibility that there was negligence on the part of the Department of Health or NHS in the matter?

Mr. Denham : In preparation for the debate and in discussion with my colleagues, I have seen no evidence that would persuade me of the need for a public inquiry or further examination of the history of the matter. Although it is outside my responsibility, I understand that the Scottish inquiry relates to a specific issue. Officials within the Scottish Executive Health and Community Care Department have been asked to examine the circumstances surrounding the introduction of heat treatment with factor 8 in Scotland in the mid-1980s, with specific reference to an alleged discrepancy between England and Scotland. It is not a

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general inquiry into the history of the matter but into a specific issue of the timing and sequence of events. The Scottish Executive awaits the outcome of those findings.

Mr. Mates : Yes, there was a difference, but some of the blood products that was processed in Scotland was given to patients in England because it was issued throughout the United Kingdom. What will the Minister do if the Scottish Parliament decides to compensate Scottish hepatitis C sufferers? Will he maintain his present position? That would be intolerable.

Mr. Denham : The hon. Gentleman, not unreasonably, strings together a sequence of hypotheses. Clearly, any information that becomes available as a result of the Scottish inquiry would need to be carefully considered if it is relevant to the responsibilities of English Ministers, but it is not helpful to speculate on the possible outcome of the inquiry.

I want to consider some other important issues that were raised in the debate.

We have referred the new licensed combination therapy to NICE.

Mr. Hancock : Will the hon. Gentleman give way on that point?

Mr. Denham : I should like to make progress because many other important issues have been raised, including counselling.

We are working closely with the Haemophilia Society, through a grant towards its administration. During the past two years we have supported the society's project to develop and produce information on hepatitis C for young people, their families and teachers. The material is sensible, informative and lively. We are also funding a seminar later this year for professionals on co-infection with HIV and hepatitis C. We shall continue to build on our work with the society. My ministerial colleagues have met its representatives and found the exchanges helpful.

We must take the work forward in several ways. An external group--the haemophiliac alliance--will provide additional pressure on Government. My colleague Baroness Hayman, the then Minister, wrote to welcome its formation. It is bringing together the professional groups dealing with haemophilia care, for which it is drawing up a service specification. When completed, the specification will be a significant tool for those commissioning haemophilia services, acting as an outline of the key components of a high-quality service. The alliance has asked the NHS Executive to circulate information about its service specification work via the national networks, and that is being done. Haemophilia services appropriate for specialist commissioning has been identified and three regional specialised commissioning groups--in London, the west midlands, and the south-east--are studying them.

The hon. Member for Runnymede and Weybridge (Mr. Hammond) asked about the way in which we were

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developing and supporting guidance for the service. That is one way in which we are doing that. We have also funded a group from the Royal College of Physicians, the British Society of Gastroenterology and the British Association for the Study of the Liver to draw up evidence-based clinical guidelines for the management of patients with hepatitis C, which should be available later this year.

We have also asked the UK Haemophilia Centre directors to ensure that counselling is available and accessible to haemophiliacs with hepatitis C. Several hon. Members have raised that issue. We must ensure that the facilities at the 22 comprehensive care centres are extended to the 100 or so smaller haemophilia centres. We are also working with the directors on collecting better data on the number of people with haemophilia who are infected with hepatitis C. As the hon. Member for East Hampshire said in his opening remarks, the Haemophilia Society and others are keen to have the information.

We are always open to new ideas about the way in which we might improve the lives of people with haemophilia and hepatitis C. The hon. Member for Portsmouth, South (Mr. Hancock) raised the issue of insurance cover. My colleague, the noble Lord Hunt, is writing to the Association of British Insurers on easing the barriers to insurance cover. I would not wish anyone to feel that our agenda on such issues was closed. I invite hon. Members to contact us with other issues that they think that the Government should be advancing.

I acknowledge the point of the hon. Member for Runnymede and Weybridge that we must consider hepatitis C in a wider context. It is a significant public health issue, and it is important that we increase knowledge about its natural history, prevalence, transmission and treatment, so that the NHS might be equipped to deliver services based on the best scientific and medical evidence available.

We have commissioned research worth about £1 million, and we are investing a further £500,000 of research moneys specifically in research into hepatitis C and injecting drug misuse, which is responsible for most new cases. The research will investigate ways of reducing the incidence, spread and progression of the disease.

Mr. Hancock : Will the Minister give a final assurance that combination therapy will be available throughout the regions of the UK for which he is responsible to any haemophiliac suffering from hepatitis C?

Mr. Denham : If NICE is to be effective, we must await its guidance and not seek to pre-empt it. NICE has been created because, in too many areas, the national health service has lacked authoritative guidance on the clinical effectiveness and the cost effectiveness of treatments. Its creation enables us to refer therapies that have spread more slowly than expected, and treatments where there are concerns about effectiveness. Once a referral is made to it, it is important for Ministers to await its independent judgment. When that guidance is received--

Madam Deputy Speaker (Mrs. Gwyneth Dunwoody): Order.

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