Lord Darzi Hansard - Health Bill amendment 28 April 2009

# Amendment 4

### Moved by Lord Morris of Manchester

4: Clause 2, page 2, line 4, at end insert—

"() the Advisory Committee on the Treatment of Haemophilia;"

**Lord Morris of Manchester:** My Lords, I want first to thank my noble friend Lady Thornton for doing so much to make it possible for this debate to take place at a time when my dear and inspirational friend, the noble Baroness, Lady Campbell of Surbiton, can be with us. As she said so movingly and so memorably in the debate on the Archer report last Thursday, the history of the contaminated blood disaster is one of unspeakable suffering for,

"mothers, fathers, sisters, brothers, wives, husbands and friends ... seeing their loved ones die".—[Official Report, 23/4/09; col. 1614.]

When I announced the setting-up of the Archer inquiry in February 2007, 1,757 patients had died. Since then, of a patient group of barely 5,000, over 200 more have died in direct consequence of the use of contaminated blood in their NHS treatment. The noble Baroness, Lady Campbell, was herself widowed by the disaster, and I know that the House very much looks forward to hearing her speak again.

Today's is the third debate in which the case for my proposed new clause will have been addressed; and I will not be returning to questions dealt with in Committee and last Thursday. However, many of the questions then raised went unanswered due, not least, to pressure of time, and there are some that must be pursued today. I refer not only to questions of mine but to

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those of other participants, including the noble Lords, Lord Thomas of Gresford, Lord Corbett and Lord Rooker, and the noble Baronesses, Lady Campbell, Lady Barker and Lady Morris of Bolton.

The first unanswered question is whether it is now clearly understood by the department that the body for which my proposed new clause provides would be a statutory one. Correspondence between the department and the Haemophilia Society envisages a non-statutory body and is at variance with the intention of the Archer report. Thus it will be helpful if my noble friend Lord Darzi, in replying to this debate, can clarify the department's intended response.

5 pm

I turn now to the urgency of the need for an updating of ministerial Statements to Parliament on the sombre threat of a third deadly scourge to patients dependent on NHS blood and blood products. The vCJD threat is increasingly worrying, a recent post-mortem on a hepatitis C-infected patient having found variant CJD in his spleen, thus totally undermining the Chief Medical Officer's assessment of the risk as "hypothetical". Specifically, we need to know the department's current figure for the number of patients treated with blood taken from variant CJD-infected donors. We need also to know what action Ministers have taken since the post-mortem on the implications of its findings. Further, how do they now assess the risk facing patients treated with blood taken from such donors, and what protection is now in place to safeguard recipients of donated blood?

As the noble Lord, Lord Thomas of Gresford, said, the issue of Crown immunity must also be pursued. The Archer inquiry's report raised it in commenting on the behaviour of the Blood Products Laboratory—the BPL—and said:

"In July 1979, the Medicines Inspectorate visited BPL. They reported that the buildings were never designed for the scale of production envisaged. They commented: 'If this were a commercial operation we would have no hesitation in recommending that manufacture should cease until the facility was upgraded to a minimum acceptable level'".

The Archer report then starkly stated:

"BPL was rescued by Crown Immunity"-

and went on that BPL's,

"existing plant continued production, relying on Crown Immunity to dispense with the requirements of the Medicines Act, but was able to meet only 40 per cent of the national requirements".

Thus, by the use of Crown immunity, a relic of feudal England, the lives of countless haemophilia patients were blatantly and gravely put at risk.

Speaking in the House on 10 March, my noble friend Lord Darzi, responding to me in exchanges about thalidomide, referred to,

"the tremendous amount of work that has gone into the marketing, testing and regulation of drugs, as encapsulated in the Medicines Act 1968, from which society has benefited greatly".—[*Official Report*, 10/3/09; col. 1059.]

There could be no clearer text than this for describing the enormity of the BPL's use of Crown immunity to dispense with all the requirements of that renowned and so vitally important statute; hence the need to reflect again in this debate on from whom the BPL was "rescued" by its use of Crown immunity.

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First and foremost, of course, it was "rescued" from the afflicted and bereaved by the disaster, thereby denying them any prospect of legal redress, a denial made all the more cruelly unjust by the refusals of successive Governments to agree to a public inquiry. So they were left with no hope of any independent assessment of responsibility for their plight until the Archer inquiry was announced.

Crown immunity has now been abolished. It was ended by John Major's Conservative Government in 1991, and infected NHS patients ask why the present Government, who clearly have no intention of reinstating Crown immunity, cannot now review the claims of the victims contaminated by NHS blood from whom the BPL was "rescued" by Crown immunity. The noble Lord, Lord Thomas of Gresford, said in his speech last Thursday that he was sure that it would be possible for actions to be brought now if the Government, opposed as they must surely be to Crown immunity, considered this possibility?

Most of all, we need to know in this debate when the Government now expect to respond to the Archer report as a whole and how we can be sure that parliamentary time will be found for their response to be fully debated in your Lordships' House. Meanwhile, I hope that a positive response to this new clause—one giving a clear pointer to the Government's intentions vis- -vis the report as a whole—will be forthcoming.

As I made clear both in Committee and elsewhere, the new clause can be implemented at no great cost but much to the relief of haemophilia patients who feel strongly that there must be no delay now in creating a statutory committee to advise government on the management of haemophilia, with patient and family representation. Of course there will be costs in giving full effect to the Archer report, but there will also be priceless benefits in enabling haemophilia patients to live fuller and more fulfilling lives.

Naturally, their principal desire is for closure with the Department of Health on their claims for just treatment. As the noble Baroness, Lady Morris of Bolton, told the House last Thursday:

"When we are ill, we have faith that the treatment that we receive will help to make us better, or will help us to manage the disease so that we can lead as full and dignified a life as possible. To receive treatment that leads to such tragic consequences is unimaginably cruel".—[*Official Report*, 23/4/09; col. 1628.]

Surely parliamentarians have no more compelling duty than to them.

It may, however, be said that, self-evident though the Archer report has made the case for closure, a time of deep recession is not one in which to expect it to be achieved. Yet some aspects of the current difficulties are frequently compared, not inappropriately, with those faced by Denis Healey—now my noble friend Lord Healey—when he was Chancellor of the Exchequer and had to resort to the IMF for support. Harold Wilson, then Prime Minister, in whose Government I served, said that it was a time for the broadest backs to bear the biggest burdens, but he needed no reminding that my responsibilities, as the first Minister for Disabled People, were for those with broken backs and even more handicapping disabilities. He and Denis Healey

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readily enabled me to introduce a severe disability allowance, the mobility allowance, the carers' allowance and many other benefits which both Harold Wilson and Denis Healey said later were the Government's finest achievements.

I hope that may put in some perspective the cries of alarm from anyone who thinks that acting justly to this small and stricken patient community is insupportable. Its claims are entitled to be seen as a priority of priorities and I know that my noble friend Lord Darzi will want to reply as helpfully as he can. I look forward to hearing him as we proceed.

**Baroness Campbell of Surbiton:** My Lords, I am delighted to have the opportunity to speak in support of the amendment tabled by the noble Lord, Lord Morris of Manchester, who has made an extremely successful case for it. I ask noble Lords on all sides of the House to support this amendment, which, if passed by your Lordships, would establish a statutory committee to provide and give advice to government and haemophiliacs on health and support services.

This committee would undoubtedly improve the lives of those who have suffered from contaminated blood products. It would also bring together information for haemophiliacs and those who have cared for them into one place, with punch. I am not saying that there are no places to go for information, advice and support; the Haemophilia Society has done wonderful things. It is time, however, for a statutory committee that can really punch above its weight.

I shall not repeat my reasons for supporting the amendment. It is quite difficult for me to say these words, which take me back to an extremely difficult time in my life. Noble Lords will recall my connection with the haemophilia community and my experience, when my husband was contaminated in the mid-1980s, of trying to get coherent information and advice. If only we had had this committee then.

The committee would not be bureaucratic or cumbersome; it would be small and cheap to maintain. It would right a great wrong that has been done to haemophiliacs over so many years. Those who live with the complexities of their condition plus the consequences of contaminated blood—and all that that brings—should have the best information, support and advice. I believe that this committee would establish a modern response to a 1980s disaster and I urge noble Lords to support the amendment proposed by the noble Lord, Lord Morris of Manchester.

**Baroness Howarth of Breckland:** My Lords, this is a difficult speech to make, because I have unutterable respect for both previous speakers and a great belief that such a committee might well be a positive way forward. I was going to speak about any section or interest that was added to this list because I feel that, if one group is

added, I should bring forward a range of others who have an equal wish to be represented in the Bill. I find this difficult because the noble Lord, Lord Morris, and the noble Baroness, Lady Campbell, are wonderful advocates for this cause, but others of your Lordships might have advocated other causes had they thought that they might be added to the list in this part of the Bill.

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Having said that, I hope that my noble friends will understand that I am not speaking against the need for an advisory committee; that need is a different issue from the consultation item under discussion, which is in a list in the Bill. If the need for an advisory committee was brought forward in another place, as I think will happen, I would be able to support it. It is with deep regret, then, that I feel unable to support my noble friends; it is simply because they are, as a technicality, making their argument in the wrong place. Should they put this forward at Third Reading, I would have to bring a long list of other people who would also wish to have their views heard.

**Baroness Finlay of Llandaff:** My Lords, I intervene briefly after the powerful speeches made by the noble Lord, Lord Morris, and the noble Baroness, Lady Campbell. They made an important point. People have to trust the healthcare professionals who look after them; they have no choice but to trust the service to give them what they need. Therefore, at some future time, we might well be able to establish some grouping that would make representations for those who have, unwittingly and inadvertently, been the victims of a mishap that has occurred. If that is the case, such a committee should be included in this core list of bodies for which the NHS Constitution would be very important. Although the name outlined in the amendment may not, I fear, be right, the principle is correct. I wonder whether the Minister might be able between now and Third Reading to come back to us with some assurance that whatever comes in the future could be added to a broader grouping, and that the grouping outlined in the Bill may be a minimum, but not an exclusive, list.

#### 5.15 pm

**Earl Howe:** My Lords, it is not for me to speak on behalf of the noble Lord, Lord Morris of Manchester, but I think it might help the House to know—the noble Lord can correct me if I am mistaken—that the substantive amendment in this group is Amendment 40, and that the amendment that we are now debating is a pragmatic device, if I can put it that way, to ensure that we debate this very important topic at a time convenient to most of your Lordships. I say that only to address the point made by the noble Baroness, Lady Howarth, who was perfectly right in her observations about the list, but I do not think—if I read the noble Lord, Lord Morris, correctly—that that was his prime intention.

Like other noble Lords, I take my hat off to the noble Lord, Lord Morris of Manchester, for his principled and deeply felt stand on the plight of haemophiliacs in our country. In Grand Committee, as well as on Thursday of last week and again today, he cogently argued the case for treating fairly and compassionately those individuals, a dwindling band of people whose privations have been, and continue to be, so great. It would be a hard-hearted person who could read the report, so excellently written by the noble and learned Lord, Lord Archer, and not associate himself with the call that he makes for speedy and appropriate government action.

It was disappointing that the Minister was unable to throw any light on the Government's detailed thinking when she replied to the Motion of the noble Lord,

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Lord Morris, last week. She indicated then that she was pushing hard to be able to do so today. I hope that she can, or that her noble friend can.

Only last week, I was contacted by one of the people who received contaminated blood. She was not at all strident or pushy in her tone; she merely wished me to know that the hepatitis C which she contracted through no fault of her own as a result of the transfusion had now developed into full-blown cirrhosis of the liver. Her lifespan as a result can now be measured in terms of a few years at best. A liver transplant, she told me, is unlikely to be a practical possibility, not least because she has to take her turn in the queue. No allowance is made by the NHS for the fact that the NHS itself was the instrument of the serious illness which she now suffers from. Indeed, the attitude that she encounters in the NHS can be one of criticism, as if it were her own lifestyle that were to blame. That is a double insult.

It is the needs and wishes of that lady and individuals like her that most concern me here, rather than the business of attributing responsibility for what happened in the 1970s and 1980s. To be sure, it is important to establish what happened and why and to learn lessons for the future, but the immediate and pressing question is to ask what are the needs of the people who are now, many of them, very ill. What can and should we do to make their lives more bearable? As the noble and learned Lord, Lord Archer, recommended, we should look at ways in which access to NHS services for this group of people could be improved.

It is here that a committee of the kind proposed by the noble and learned Lord, Lord Archer, and now by the noble Lord, Lord Morris, could have a useful role to play. It is not the only way of dealing with the matter, but one factor in its favour is that it would provide the haemophiliac community with the sense that it was being listened to by a group whose remit consisted solely of haemophilia and related issues. As the committee would be only advisory, it would not usurp the authority of the Secretary of State, with whom decisions would ultimately rest, but its recommendations would clearly carry considerable moral weight.

I very much hope that the Minister will be in a position today to indicate the Government's response in more than just a cursory fashion to the proposals so cogently made by the noble and learned Lord, Lord Archer.

**Baroness Wilkins:** My Lords, I strongly support the purpose behind this amendment, as set out by the noble Earl. The establishment of a statutory committee was one of the strongest recommendations of the excellent Archer inquiry. I support the amendment for its support of this recommendation.

**Baroness Tonge:** My Lords, I, too, add my support to the spirit of this amendment if not to its actuality—if that is the right word. I also add my support to the remarks of the noble Baronesses, Lady Howarth and Lady Finlay. I have just been to a meeting in the other place on brain tumours and research into brain tumours in children, which is greatly neglected. There are many groups who would like to be mentioned in this Bill, which is why we are reluctant to add this group. But—and it is a very big but—this saga has gone on for far too long. It is quite disgraceful that these

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people have not been dealt with justly and efficiently before now. I congratulate the noble and learned Lord, Lord Archer, the noble Lord, Lord Morris, and the noble Baroness, Lady Campbell, on taking every opportunity they possibly can to raise this issue. I admire them, I envy them and I try to be like them. I hope they will carry on campaigning and raising this issue until we get satisfaction for this group of patients.

**Lord Darzi of Denham:** My Lords, I also acknowledge the moving speeches made by my noble friend Lord Morris and the noble Baroness, Lady Campbell.

Amendment 4 is a device to allow this important matter to be debated early in proceedings. I am grateful to the opposition parties for their help and support in facilitating this. As we heard, Amendment 40, tabled by my noble friend Lord Morris, is based on a recommendation by my noble and learned friend Lord Archer in his report published on 23 February. The report considered the supply of virus-contaminated blood and blood products and its devastating effect on the haemophilia community in particular from the early 1970s onwards until tests became available for Hepatitis C and HIV. We welcome my noble and learned friend's report and warmly thank him and my noble friends Lord Morris and Lord Corbett for the efforts they are making on behalf of the haemophilia patients and their families.

There is no doubt, as the noble Baroness, Lady Tonge, pointed out, that this group of patients has suffered tragic consequences as the result of the serious infections that were inadvertently transmitted via this treatment. I agree that it is important to ensure that these patients and their families are properly supported and to act to reduce as far as practically possible any further risk to all patients who need blood and blood products. There have been major advances in safer treatments for haemophilia. We have committed to making available synthetic products not derived from human blood for all those patients for whom they are suitable.

Haemophilia patients together with their clinicians and service commissioners already have influence in the selection, procurement and delivery of those products. This will continue. We entirely agree with the arguments in my noble and learned friend's report that it is vital for patients to be represented where decisions about good practice in healthcare provision are being made. This was the centrepiece of our strategy for embedding quality in the NHS and it certainly ran through my report, *High Quality*  *Care for All.* Together with effectiveness and safety, patient experience is a guiding principle for high-quality healthcare.

We agree that it is vital to have strong mechanisms in place to provide independent expert advice on blood safety, and to recommend improvements. We have an established mechanism to do this through the expert scientific Advisory Committee on the Safety of Blood, Tissues and Organs, which advises the UK Administrations. The committee has patient representation and is developing effective means of communicating its advice for stakeholders and the public. Our view is that it is better to build on existing arrangements and expertise, rather than risk disrupting or duplicating those arrangements via legislation.

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With this in mind, one option that we are actively considering, and have already discussed with the noble Lord, Lord Morris, is that together with the devolved Administrations we could build on the existing UK-wide partnership in the Haemophilia Alliance between patients, haemophilia doctors and others involved in their care, such as nurses, physiotherapists and social workers. The alliance is jointly chaired by the Haemophilia Society. We are considering a formal arrangement whereby the Government would seek advice from the alliance on matters relating specifically to the care of haemophilia patients, and meet with them at least twice a year. If this were pursued, we would, of course, meet the costs of these meetings. The Haemophilia Alliance has already established a commendable reputation by developing a national service specification for bleeding disorders, which has been welcomed by commissioners.

I assure noble Lords that my right honourable friend the Secretary of State is looking at the most appropriate means of strengthening representation for haemophilia patients and ensuring that advice is provided to those best placed to act on it for the benefit of patients. This is being considered together with the other recommendations from the noble and learned Lord, Lord Archer, for improving support more widely to the haemophilia community. I personally commit to do everything possible to ensure that the Government respond fully to the noble and learned Lord's recommendations in advance of the Whitsun Recess, if not the week before. Furthermore, we will of course assist as far as possible in securing a debate on the Government's response.

Finally, I turn to two points made by the noble Lord, Lord Morris, on CJD. First, since the announcement of the finding of the case, much careful work has been undertaken to ascertain the possible source of this infection. The information will be considered by the CJD incident panel, which will advise if further action is necessary. I remind the House that we have implemented many precautionary measures to reduce the risk as far as is practical and continue to monitor this area very closely. Secondly, on Crown immunity, I reassure my noble friend that the position is very different from what it was 20 or 30 years ago, but I am more than happy to look at what Crown immunity was 30 years ago and respond, giving the changes that have occurred since then.

I hope that the noble Lord will feel reassured by the steps that have been taken to consider the most appropriate way in which to involve those affected by haemophilia in decision-making and feel able to withdraw his amendment.

Lord Morris of Manchester: My Lords, I think it was Aristotle—if not it ought to have been—who said that it is the essence of probability that some improbable things will happen. How could I possibly have suspected that my first duty now would be for me to thank the noble Earl, Lord Howe, for speaking so eloquently and with such attention to accuracy in responding to the noble Baroness, Lady Howarth? As he explained, I was simply taking the first opportunity to raise again an issue that noble Lords in all parts of the House see as one of priority and very considerable importance to the future of the National Health Service. The pledges

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we have had from my noble friend Lord Darzi on the imminence of a full response to the Archer report, and what he said about using his best endeavours to find parliamentary time for it to be debated, go far enough for me. I beg leave to withdraw the amendment.

Amendment 4 withdrawn.