

Hepatitis C (Haemophiliacs)

Motion made, and Question proposed, That the sitting be now adjourned." (Amber Rudd.)

09:30:00

Paul Goggins (Wythenshawe and Sale East) (Lab)

I am grateful to have the opportunity once again to draw the attention of the House and of Ministers to the injustice that still faces those who in the 1970s and 1980s became infected as a result of treatment with contaminated blood products.

Let me say at the outset that, although I seek in this debate to highlight the particular issues and concerns of those with haemophilia who were infected with hepatitis C, I recognise, of course, that the issues affect others beyond that group. Many haemophiliacs received other infections, HIV in particular, and some were dual-infected with HIV and hepatitis C. Others were multi-infected by the range of other viruses to which they were exposed. Some haemophiliacs were treated with blood taken from donors who later died from CJD. Others did not have haemophilia, but were none the less infected as a result of their NHS treatment. I am sure that some who contribute to the debate later will refer to the experience of those who have been affected in those other ways, and a number of points I will make will have a broader relevance to those people's situations.

The reason that I selected financial support for people with haemophilia infected with hepatitis C as a topic for debate is simple: it reflects the specific concerns of three of my constituents with whom I have been campaigning on the issue for 16 years. They are Peter Mossman, Fred Bates and Eleanor Bates, who is Fred's wife. I pay tribute to their determination and the single-minded way in which they have worked with other members of the haemophilia community in pursuit of justice and truth.

I am delighted that you, Mr Dobbin, will oversee our proceedings this morning, although given your keen interest in the topic, I suspect that a bit of you would like to participate.

Mr Jim Cunningham (Coventry South) (Lab)

I congratulate my right hon. Friend on securing the debate, which is one of many over the years. Does he, like me, think and hope that the Minister will give positive answers this morning, given the many debates in the past, so that the people affected can experience justice?

Paul Goggins

I am grateful to my hon. Friend for that intervention. He makes precisely the point I was moving on to. I welcome the new Minister, the hon. Member for Battersea (Jane Ellison), to the debate and to her new responsibilities. Whatever else she achieves in her time as a Minister—and I hope she achieves a great deal—nothing would be more important than bringing a measure of justice to those who have suffered from such injustice over so many years. Lord Winston described it as the worst treatment disaster in the history of the NHS.

I am delighted that we are joined this morning by so many hon. Members from both sides of the House—particularly the hon. Member for North East Bedfordshire (Alistair Burt), who raised the issue again with the Prime Minister in a clear and determined way a few days ago. I am also pleased that my right hon. Friend the Member for Leigh (Andy Burnham) is in attendance for the start of the debate. It is unusual for a Secretary of State, or shadow Secretary of State, to attend an Adjournment debate in Westminster Hall. His attendance is appreciated; he is keeping a promise made earlier this year. My constituents have asked me to thank him this morning for his willingness to listen—not only now in opposition, but when he was the Secretary of State.

Andy Burnham (Leigh) (Lab)

I apologise, Mr Dobbin, for the fact that I cannot stay for the whole debate. I am here to show solidarity with my right hon. Friend the Member for Wythenshawe and Sale East (Paul Goggins), who has represented his constituents outstandingly, and with Peter Mossman and Fred and Eleanor Bates, whom I met in my office with my right hon. Friend when I was Health Secretary.

I want my right hon. Friend and his constituents to understand that the commitment I gave to them was not a one-off, convenient commitment, but a permanent one. If I were to find myself back in government, that commitment would remain. Does my right hon. Friend agree that there needs to be a further process of truth and reconciliation, so that those concerned have all the answers for which they are still looking?

Paul Goggins

I am grateful to my right hon. Friend and I agree with him entirely. There needs to be not only a review of the current financial arrangements, but a deeper search for the truth, to bring justice, an explanation and a profound apology to those who have suffered. I will make some remarks about that later.

I will not dwell this morning on the long history of the injustice, other than to remind the House that of the 4,670 people with haemophilia who were infected with hepatitis C or HIV, at least 1,757 have died from the effects of the viruses; I say "at least" because the number is almost certainly higher than that. Although it was recognised at the time that the use of imported blood products carried a very high risk, treatment continued and patients were simply kept in the dark. As people tried to get to the truth, they were met with a lack of honesty and deep disrespect. Their dogged persistence is remarkable.

Mr Tom Clarke (Coatbridge, Chryston and Bellshill) (Lab)

I congratulate my right hon. Friend on his excellent speech, the work he has been doing and obtaining the debate. I know that the debate and the figures he gave relate mainly to England. His late friend and mine "his predecessor, Alf Morris" would be proud of the work he is doing.

Would my right hon. Friend allow me to introduce one Scottish aspect to the discussion? In Scotland, the Penrose inquiry is taking evidence on a wider range of issues than has so far been possible in this House, including about what steps were taken to protect the public, given the clinical knowledge available at the time. Without delaying the action for which he urgently calls, would he take that on board and would the Minister reflect those views?

Paul Goggins

I am grateful for my right hon. Friend's intervention. He is a fine campaigner on a range of issues, but on none more so than this. He did great work with my predecessor, the late Alf Morris. I referred to my 16 years of campaigning with Fred, Eleanor and Peter, but I was, of course, only picking up the baton; Alf had worked with them tirelessly for many years.

My right hon. Friend raises a pertinent point about Penrose, because when he reports no Government will be able sit back and do nothing. Profound questions will be posed by that report and they will apply every bit as much here as they do in Scotland. I am grateful to my right hon. Friend for his timely reminder.

In January 2011, two years after the independent inquiry led by Lord Archer of Sandwell, the Government concluded a review of the support available to those who had been infected with hepatitis C and HIV. Along with others, at the time I welcomed the additional lump sum and annual payments to those infected with hepatitis C who had reached the so-called stage 2 "essentially, where cirrhosis has been diagnosed. Other improvements were made, but it was clear to many of us from the outset that for the vast majority nothing would change; they would continue to suffer without the help they needed and were owed. That suffering is deepened by the confusing arrangement of the funds that are meant to help them.

In April, the Minister's predecessor attended a meeting of the all-party group on haemophilia and contaminated blood. I see a number of right hon. and hon. Members here who were present at that meeting; they will remember that it was fairly stormy and that a range of views were expressed about the funds. Those present will remember what was said. I made a note of some of the comments: "It is utterly bizarre....so many funds"; "a nightmare of bureaucracy"; "something is badly wrong"; and "it is not acceptable to have to go cap in hand". Those comments were all made by the Minister's predecessor, leaving those who attended wondering why she had not come to the meeting with solutions rather than joining in the chorus of criticism.

My constituents want one fund for haemophiliacs with hepatitis C, essentially bringing together those parts of the Skipton Fund and the Caxton Foundation that currently administer the limited financial support available. They believe that that would reduce bureaucracy and, more importantly, enable those who manage the funds to increase focus on their specific needs. Although they acknowledge others' needs, they want and are entitled to a better response than they currently receive.

Within the new fund, the immediate priority should be a complete overhaul of the stage 2 assessment. Currently, the lump sum and annual payments start only after hepatitis C has caused cirrhosis. Three out of four people registered at stage 1 do not progress to stage 2, even though they, too, experience extreme and severe symptoms, including great fatigue and often painful bleeds.

The discrimination between those at stage 1 and stage 2 has been brought home to me through my constituents' experience. Over the many years I have known Peter Mossman and Fred Bates, I have seen them on good days and bad. I have seen them in pain and distress, but I am aware that their most painful moments have been at times when I have not seen them, because they have not been able to get out of bed and out of the house. They suffer similarly, but one of them is at stage 1 and one is at stage 2.

The discrimination is as incomprehensible as it is unjust, and it has enormous consequences. Those at stage 1 receive a one-off payment of £20,000; those at stage 2 receive an additional £50,000 lump sum plus an annual payment, which is currently £14,191. The Minister should scrap this crude distinction and urgently consider implementing a wider assessment of the health and well-being of each individual. The payments are intended to help people cope with the difficulties that they face, and more should benefit from them.

David Simpson (Upper Bann) (DUP)

Like others, I congratulate the right hon. Gentleman on securing this important debate. This issue started in the 1970s, so the problem has now been with us for 43 years. More than 80% of the individuals with a bleeding disorder did not benefit from any ongoing payments for a long time. That must be rectified. The Government must review immediately how the issue is handled.

Paul Goggins

I am grateful for the hon. Gentleman's support for that argument. Differentiating between stage 1 and stage 2 creates a false and discriminatory division. It is not acceptable, and it does not help the many people registered at stage 1 who are not at stage 2 because they have not been diagnosed with cirrhosis, but who still often live in great pain and distress. It is vital that they get the financial and other help that they absolutely need.

Currently, the Caxton Foundation must try through discretionary payments to address the urgent needs of those at both stage 1 and stage 2. The fund simply does not have enough money, and as decisions are made about whose need is greater, recipients feel as though they must beg even for essentials. Ministers will need to obtain and share more accurate data, particularly to assess how many of those registered at stage 1 have died and what the likely financial costs would be of a revised arrangement between stages 1 and 2. That information is vital, but one fund with the resources to make lump-sum and annual payments to all those who need them is an essential first step.

Other issues must also be addressed. People with or without haemophilia who have been infected with hepatitis C should be exempt from the employment and support allowance work capability assessment and placed automatically in the support group. It heaps indignity on injustice to put them through the Atos back-to-work test when work is simply impossible for the vast majority of them. Will the Minister hold urgent discussions with the Secretary of State for Work and Pensions with a view to creating that exemption? It would be compassionate, relatively inexpensive and a clear indication that she means business.

I also ask the Minister to consider the specific needs of those, such as my constituent Eleanor Bates, who care for their loved ones. The Caxton Foundation is meant to help them, but they frequently feel that they are last in the queue. Their lives have also been affected deeply by their partners' infection, and their needs as carers must be addressed.

Reforming the funds and providing a fairer, more effective system of financial support would be an important step in the right direction, but no debate about the issue should omit the need for a proper acknowledgement of what took place and why, and a profound and sincere apology for the suffering created by the disaster. Campaigners still want a public inquiry, and I support fully their calls for transparency and accountability.

If the Government continue to set their face against a formal public inquiry, they should, in my view, consider other mechanisms established in the recent past to get at the truth of an historic wrong. Two years ago, the Prime Minister commissioned the highly respected lawyer Sir Desmond de Silva to undertake a full investigation into the circumstances surrounding the death of the Northern Ireland solicitor Pat Finucane in 1989. Although this approach was not welcomed by Mr Finucane's family, Sir Desmond had access to all the intelligence files, Cabinet papers and earlier reports, and concluded that there had been what the Prime Minister described last December as "shocking" levels of state collusion.

In relation to another tragedy that took place in 1989 "I am pleased that my right hon. Friend the Member for Leigh is still here" the Hillsborough independent panel, which was welcomed by the families of the 96 people who died at the FA cup semi-final, also demonstrated a determination to get to the truth. As a result of the report, inquests have now been reopened.

Whatever Ministers decide to do in this case must, of course, be discussed with those whose lives have been directly affected. Continuing to do nothing is simply not acceptable. A serious Government-backed inquiry must be held, with access to all the remaining records and the power finally to get to the truth of what happened and why. In addition to fair financial support, those who have suffered so much are still owed a full explanation and a sincere, profound apology.

09:47:00

Jim Shannon (Strangford) (DUP)

I congratulate the right hon. Member for Wythenshawe and Sale East (Paul Goggins) on bringing this important matter to the House's consideration. I will speak specifically on behalf of my constituents, as I think will everyone who speaks today, from a heartfelt understanding of the problems that those constituents have faced for a number of years. My hon. Friend the Member for Upper Bann (David Simpson) illustrated the time scale. If ever there were a powerful case for the Minister to answer, this is one. Many of the speeches made today will be impassioned. I welcome the Under-Secretary of State for Health, the hon. Member for Battersea (Jane Ellison) to her position, and I look forward to working together on many issues in future.

The background to the case is clear. I have spoken to constituents of mine who are victims. Some of my constituents live daily with these illnesses through no fault of their own but rather as a result of the Government's inaction at a time when action was important. My constituents have sent me a briefing, and I have relied on them for information as well as for the personal details that they have given me, although I do not intend to mention any names out of respect for confidentiality and personal



issues.

The Archer inquiry investigated the fact that between the 1970s and late 1980s, 4,670 people with haemophilia were infected with hepatitis C through treatment by the NHS that they loved and respected, which ultimately, unfortunately, let them down. Of those, 1,243 people with haemophilia were also exposed to HIV, as the right hon. Gentleman said. Almost half of those infected with hepatitis C and almost three quarters of those co-infected with HIV have since died and many have tragically left families behind. When looking at the impact on the individuals, we can never forget about the effect on their families; many individuals have experienced poverty and discrimination as a result of their infections. People, either through mistrust or lack of knowledge, sometimes unfairly discriminate against those with infections. The provisions recommended by the Archer inquiry would offer appropriate support and compensation to those affected and would ensure that steps were taken to improve blood safety.

The previous Government argued that the reason why financial support was not made available at comparable levels to those in the Republic of Ireland, for example, was that the disaster affected the two countries differently. I am unsure how that was worked out. Perhaps the disaster was measured in numbers, but the disaster is the same to each individual and each family. No-fault Government payment schemes were established to provide support to those affected. The Archer inquiry, which was non-statutory and funded from private donations, reported in February 2009 on the Government's response. Among its recommendations was a call for reform of support for those affected in line with the scheme used in the Republic of Ireland. If we had had in Northern Ireland and the rest of the United Kingdom a scheme similar to that of the Republic of Ireland, our constituents would have been much more satisfied. What does the Minister think about the Republic of Ireland's scheme? Is it possible that we can try to match it?

Despite the Government's announcing on 10 January 2011 an increase in payments to some of those infected with hepatitis C, what has been put in place is not adequate to support people through their illnesses. The Government's scheme now has two stages, as outlined by the right hon. Member for Wythenshawe and Sale East. A first stage payment of £20,000 is available to eligible people. Following that, successful recipients of the first stage payment whose hepatitis C infection has led to advanced liver disease can receive a second stage payment of £50,000. Those who have received the second stage payment are also entitled to additional annual payments of £14,000, paid monthly or quarterly. The money may look good and it sounds like a lot of support, but, as always, there is more than meets the eye to the press release. As the saying goes, the devil is in the detail, and that is clearly the case here. The Hepatitis C Trust supplied an interesting briefing and is calling for a rethink of the strategy and policy. The trust, with which I certainly agree, asks that the first and second stage categories be removed. As a constituent of mine said, the payment can never compensate for what has happened, but it can offer support and help people to adjust to and live a life affected by it.

People infected with hepatitis C can experience severe symptoms, including extreme fatigue, depression, aching limbs, headaches and abdominal pains, which may mean that they are unable to work for long periods of time. The right hon. Member for Wythenshawe and Sale East referred to Atos in his speech "I think it was also mentioned in an intervention. The situation of people who are unable to work for long periods of time needs to be understood. Symptoms can lead to difficulties in holding down a job and receiving an income. Sufferers rely on help from family and sometimes from other carers, and the fact that the annual sum starts only when a person's hepatitis C has caused cirrhosis does not take any of that into account. Understanding the problem is the crux of the issue. The briefing I received from the Hepatitis C Trust put it succinctly:

Some patients without cirrhosis are far more symptomatic than some who have reached that stage. Indeed, some patients die whilst still in stage 1. Therefore there should be no distinction between stage 1 and stage 2 payments for people who have been infected with hepatitis C through contaminated blood. They should be entitled to the full and on-going support immediately.

The second point raised in the briefing is that there has been no Government apology to date. The right hon. Member for Wythenshawe and Sale East referred to the Pat Finucane case and the apology that the Prime Minister made, so I urge the Minister to consider an apology for those infected, who have suffered many years of illness as a result. Having listened to some of the apologies, which should never have been uttered, that have rolled off Government Ministers's tongues to pacify and placate people for political gain, I find it difficult to believe that there has been no Government apology. I have sometimes heard Members of this House and the Prime Minister apologising on my behalf when no apology was needed and yet here, when there clearly was a fault and when innocent people lost their lives following treatment by the NHS, mouths seem to be suddenly closed. I cannot understand that mindset. A mistake was made that has cost lives and has cost other people the price of living with horrific diseases, and if that does not deserve a heartfelt apology then I am at a loss to think what does.

Mr Gregory Campbell (East Londonderry) (DUP)

Does my hon. Friend agree that what sufferers and their families need are empathy, an apology, to which he has alluded, and a commitment to ongoing support for the remainder of their days? If they saw that coming from the heart of Government, we would have accomplished a significant amount of what the right hon. Member for Wythenshawe and Sale East (Paul Goggins) and his predecessor have sought to achieve.

Jim Shannon

I thank my hon. Friend for that contribution, which refers to something that we would all want to see. I am reminded of what my mother told me as a child: "Compassion is your pain in my heart." She was referring to an understanding of the problems facing other people, which, in a way, is why we are here. We are here not just because we want to be MPs, but because we are privileged to be elected by our constituents. We see their problems and we must illustrate and expand those problems in this great House, of which we are privileged to be a part.

Grahame M. Morris (Easington) (Lab)

I congratulate the right hon. Member for Wythenshawe and Sale East (Paul Goggins) on securing a debate on this important issue.

What are the thoughts of the hon. Member for Strangford (Jim Shannon) on the role of specialist hepatitis C nurses in providing support to sufferers who are haemophiliacs and more generally? The NICE guidelines suggest a minimum of one specialist hepatitis C nurse for every 40 patients in the community and one such nurse for every 20 patients in a hospital setting. Does the hon. Gentleman think that the Government's plans to transfer resources through the clinical commissioning group allocations will help or hinder the improvement of support for hepatitis C sufferers?

Jim Shannon

I thank the hon. Gentleman for helpfully highlighting the role of specialist nurses. I hope that the Minister will be able to give us an indication of the importance of the role of nurses and therefore the importance of retaining them and ensuring that the numbers are correct.

Just a few minutes spent reading the stories of victims and their families on the taintedblood.info website brings a lump to the throat. In this House, where we have the privilege to represent our constituents, we cannot continue to leave the families behind. I wholeheartedly support the removal of the two-tier system, which would entitle people to an annual sum to help them to cope with the side effects of this terrible disease and would take a little pressure off the families who are faced with watching their loved one fade away before their eyes. It is well past time that we do the right thing by those affected, and that will not be done by separating and segregating those infected by the same disease. I urge the Minister to take on board what is said today by the right hon. Member for Wythenshawe and Sale East and others and to do the obvious and right thing by providing the apology and response that we need.

Several hon. Members roseâ€

Jim Dobbin (in the Chair)

Order. I intend to call the shadow Minister at 20 minutes to 11 and five or six hon. Members want to speak, so I ask them to watch the length of their speeches before I have to impose limits.

09:58:00

Alistair Burt (North East Bedfordshire) (Con)

I congratulate the right hon. Member for Wythenshawe and Sale East (Paul Goggins) on securing this debate. My hon. Friend the Member for Cardiff North (Jonathan Evans) and I think that this is the first debate on this subject since the death of Lord Morris of Manchester. It is therefore highly appropriate that the first debate since Alfâ€™s death was proposed by the right hon. Member for Wythenshawe and Sale East. I welcome my hon. Friend the Member for Battersea (Jane Ellison) to her new position as Under-Secretary of State for Health. Those of us who have followed her career for some time know that that is richly deserved. Perhaps the honour to set the seal on something that has been going on just that bit too long will fall to her.

Jonathan Evans (Cardiff North) (Con)

My hon. Friend and I had the honour of being in government more than 20 years ago. Looking back over those years, does he share my viewâ€from our ministerial experience, although it was not in the Department of Healthâ€that the outcome in this area has been less than satisfactory and that the issue should have been resolved a long time ago?

Alistair Burt

My hon. Friend is right. Hanging over the issue, particularly for those of us who were Ministers in successive Governments, is a sense that not enough has been done. No blame can be laid at the door of Back Benchers who have campaigned and done so much, and in their respective ways, Governments have sought over time to do something about the issue, but we are still here because of the overwhelming sense that whatever has been attempted has just not been enough.

One reason I raised the matter on the Floor of the House with the Prime Minister the other day was to capture that sense. Let me say more about that, but I shall try to be brief. I had a meeting with the then Minister with responsibility for public health, my hon. Friend the Member for Broxtowe (Anna Soubry), a few months ago. All of us have had meetings with the successive holders of that ministerial role over time. The history is familiar to us, but there is an overall sense that whatever has been triedâ€whatever honest attempts Governments have madeâ€has just not been enough.

I supported the inquiry by Lord Archer of Sandwell, and in 2010, I seconded the early-day motion that called for the passage of the Bill that Alf Morris had introduced in the Lords to put into effect the recommendations of that inquiry. I was disappointed that those provisions were not put fully into effect, although the incoming Government made the changes mentioned by the right hon. Member for Wythenshawe and Sale East. We all welcomed that at the time, while recognising that it was still not enough.

Why are we making another attempt now? As has been made clear by the presence here of the right hon. Member for Leigh (Andy Burnham), there is now a different attitude towards uncovering past wrongs. The reason why I put the case so clearly to the Prime Minister is that his record in dealing both with the aftermath of the Hillsborough panel and with Bloody Sunday has demonstrated that he is a Prime Minister who is using his position and authority to right the wrongs of the past. Bearing in mind that he has a constituent affected by the issue, we know that he has a personal interest. That combination of circumstances perhaps means that the person in place has the determination to right the wrongs of the past. If information can be put together properly, something might therefore be done.

The sense of closure that must be achieved is palpable to all of us with affected constituents. I am here because of my relationship with a goodâ€"double-infectedâ€" friend, who has informed me about such matters over the years and for whom I desperately want to achieve something.

What has got wrong and what can we put right? The first point is that the process has taken too long: since the circumstances originated, it has all taken too long.

The second point relates to accepting that something has gone wrong. Undoubtedly, Ministers have said so and made that clear, but the Governmentâ€™s acceptance of something having gone wrong has not been accompanied by the fullest disclosure of their full part. Even when the previous Government responded to the Archer inquiryâ€" they published their response on 20 May 2009â€"they still, in relation to the release of documents on their website, stated:

â€œFurther papers have been identified, which are being released today.â€

In 2009, relevant papers were still being found and put in the public domain. The Government added the claim:

â€œWe do not believe they add to our knowledgeâ€.

Well, that is for other people to judge. All this is governed by a very real sense that not enough has been disclosed. The current Penrose inquiry, which has been mentioned, may provide an opportunity to revisit that matter.

The third point is that the process has been too divisive. Sufferers have been inadvertently set against other, being asked, â€œWhat have you gotâ€"hep C, or hep C and HIV, or some other variant?â€ It should not be like that. Everyone has suffered because they were all infected by the same process at the same time, and efforts should not be made to divide people.

The fourth point is that the premise has been wrong: it just does not work to use charity law to deliver support that ought to be the Governmentâ€™s responsibility. Efforts made over the years to put matters right and make changes have not done the job. The premise needs to be scrappedâ€"it should not be thereâ€"and colleagues have mentioned that the difficulties of separating stages 1 and 2 from hepatitis C only create new barriers and yet more unhappiness and anguish.

The problem about the Macfarlane Trust, which deals with double-infected patients, is that there is a conflict between whether it should act on behalf of the Government in disbursing funds orâ€"as it should doâ€"on behalf of the beneficiaries: arguing for as much support as possible and banging the drum for them. I sense that there is a conflict, because the trust is not doing that, so it is not doing its job.

Following up the Prime Ministerâ€™s response to my question, I will have an opportunity to meet him in a couple of weeksâ€™ time, when I will be accompanied by my constituent. I hope to meet colleagues from all parties before that, just to get our lines straight, so that we can have a good go at this.

I say to thoseâ€"the Minister and her officialsâ€"who will brief the Prime Minister, â€œGo for it this time. Donâ€™t miss this opportunity.â€ There will be all the stuff in the Department about the difficulties and the things that cannot be done. They should not look at what cannot be done, but at what can be done. This is her and her Departmentâ€™s chance, on behalf of those who did not get a chance in the first place, so let us go for it.

We need a proper apology and acknowledgment by the person from whom it will mean most, as well as some form of inquiry. I liked what the right hon. Member for Wythenshawe and Sale East said about doing that differently. The Government have got to take part in it, and questions must finally be answered. There should be an acknowledgment that the compensation system and the various trusts are just not working and that there must be



a new system.

It is not for me to say what the figures for compensation should be, but in recent years, we have learned that we live in an entitlement culture: if someone walks away from a major job in a big corporation, their wallet is well padded; if someone walks away from a public sector job in the BBC, or even in some local authorities and public bodies, their wallet is well padded. What has happened to those who were wronged by the state?

To conclude, the cost of caring for the needs of those affected by the worst treatment disaster in the NHS are quantifiable; the laying to rest of a tragic incident and the righting of a wrong are priceless.

10:07:00

Diana Johnson (Kingston upon Hull North) (Lab)

It is a pleasure to serve under your chairmanship today, Mr Dobbin. I congratulate my right hon. Friend the Member for Wythenshawe and Sale East (Paul Goggins) on securing the debate on this very important issue. As he said, he has campaigned for 16 years to bring justice to this community. He set out clearly the key points about the history of what has happened and the issues that are still outstanding.

As the co-chair of the all-party group on haemophilia and contaminated blood, I am delighted to see so many right hon. and hon. Members in Westminster Hall. I particularly welcome the Minister to her role. I am sure that, like her two predecessors as Minister with responsibility for public health, she will develop a keen interest in the issue and get to grips with the points that the community still want addressed.

Although health is a devolved matter, I hope that the Government will look at what is happening north of the border and the recommendations of the Penrose inquiry that are expected in the spring of 2014 and carefully consider the Scottish Government's response to those recommendations and the lessons that we can learn in the rest of the United Kingdom.

I want to talk about four key issues that my constituent Glenn Wilkinson, the chair of the Contaminated Blood Campaign, has asked me to raise in this debate and that relate to the financial support given to this community. I want to pay tribute to his passionate commitment to seeing that justice is done. I agree with other hon. Members about the need for a much broader and deeper review of what has happened, including a public inquiry into the whole disaster.

The first of the main issues about financial support is the Caxton Foundation application process. There is general dissatisfaction with that organisation, which has been given responsibility for grants to people with hepatitis C who have received stage 1 payments from the Skipton Fund. The Caxton Foundation has given a number of assurances that the application process will become less complex, less stressful and quicker, but when we talk to the community, it says that the grant application is not improving and that, in some cases, it is becoming worse. I fully understand why many people feel that a grant-based body is not what this community deserves, but until we have a different approach, we must make the system work better for those for whom it was set up.

I have some suggestions for the Minister to consider. First, we need a clear list of what grants will be given for published on the website. The lack of clear criteria means that people feel that they are often begging. Secondly, we need a simpler application process. At present, people tell me that they believe they have applied for something only later to find that they have to fill in further forms. That feels like moving the goalposts mid-way through an application process, and it is not fair.

Thirdly, I want to see a clear statement on means-testing. At present, it is my understanding that the Caxton Foundation is not having to means-test most applications,

and some payments, such as the winter fuel payment, are paid to everyone. Why is the foundation asking applicants to complete intrusive census forms, which ask for incredibly detailed information about the circumstances of an individual or a family?

Fourthly, we need decisions about applications to be reached in a timely fashion, and a clear target should be set. Possible further measures could improve the efficiency and functioning of all the funds. Will the Minister consider the staffing levels in the schemes, because there is a restriction in place? There is also a need to look again at the availability of financial resources. The Department could introduce some support in kind. It could offer to second a public health doctor to the funds, to complete an assessment of beneficiaries' needs. That has never been done, and it would be helpful. The Department might also bring to bear its experience of procuring computer and telephone systems. The previous Minister with responsibility for public health, the hon. Member for Broxtowe (Anna Soubry), agreed to review the grant-based system because she recognised that it was demeaning. Will the Minister comment on the progress of such a review?

Hon. Members have already mentioned the unfairness of the two-stage process. I wrote to the previous Minister, asking her to set out the evidence for separating people into the two stages. In particular, I wanted to understand

whether the rationale for awarding payments to Stage 2 sufferers is based on a desire to support these with the increased costs incurred because of the disease or to compensate them for the increased risk of dying.

In her letter back to me, she argued that the decision was based on an

expert review of the evidence

and that

the decision was made not to introduce recurrent payments for all as there is a wide spectrum of illness associated with chronic hepatitis C infection.

Let me put to the Minister three reasons why that argument does not hold up. First, the distinction is not a clear one; there is no blood test. It is a matter of progression, which is not easily determined. That issue is exaggerated by the fact that it requires a liver biopsy to ascertain the level of liver damage, and that, in itself, is potentially life threatening.

Secondly, there is increased evidence that hepatitis C is more than a liver disease. Other Members have already said that a range of symptoms have been identified including fatigue, joint problems and mental health issues. Thirdly, the fact that mortality rates are higher among stage 1 sufferers than stage 2 sufferers seems to be a compelling argument why such an artificial distinction should not hold.

The Contaminated Blood Campaign has committed many hours of research to get to the bottom of the expert evidence. When Professor Brian Gazzard, who is chair of the expert panel, was asked about the matter, he said that they had never discussed the two-stage system; in fact, the experts were expressly asked by the Department of Health not to discuss it. Charles Gore, the chief executive of the Hepatitis C Trust, who was also one of the experts used by the Department of Health, has stated that the two-stage approach is an arbitrary system and that he knows of people who suffer more in stage 1 than others do in stage 2. Will the Minister set out "if she cannot do it now, perhaps she could write to me" what the expert evidence is, so that we are clear about how the decision was reached?

I have two other matters to discuss briefly. On the number of people who are affected, my right hon. Friend the Member for Coatbridge, Chryston and Bellshill (Mr Clarke) asked a parliamentary question about the number of Skipton stage 1 beneficiaries, which is unknown. Will the Department of Health take the necessary steps to identify how many stage 1 sufferers are still living? That could be done through contact information that

is still held by the Skipton Fund and/or through information now held on census forms by the Caxton Foundation.

On hepatitis C and HIV, I absolutely agree with what the hon. Member for North East Bedfordshire (Alistair Burt) said about how we set different parts of the community against one another. The list of anomalies between those infected with hepatitis C and those with HIV and their family members continues to grow. The imbalance of the system now operated by the schemes is such that some family members will get assistance and others will not. That area needs to be considered, especially because HIV and its treatment have changed considerably over the past 20 years. That needs to be recognised.

Finally, I would be delighted if the Minister accepted an invitation to come to a meeting of the APPG on haemophilia and contaminated blood.

10:15:00

Sir Nick Harvey (North Devon) (LD)

It is good, Mr Dobbin, to have the opportunity to contribute to this debate, and I applaud the right hon. Member for Wythenshawe and Sale East (Paul Goggins) for initiating it. It is also good to see the breadth of support from across the Chamber.

I represent my constituent, Sue Threakall, who has campaigned for many years with the Tainted Blood campaign and is currently the chair of that campaign. It has taken an awfully long time to get even as far as we have today. I very much support the comments that other Members have made about how unsatisfactory the situation is, even now.

I commend the right hon. Gentleman on a powerful but well measured and well judged speech. Health Ministers in Governments of each colour have, on many occasions, acknowledged that haemophiliacs are an exceptional and specific group of people affected by the contaminated blood scandal and that they merit special treatment in light of their tragic circumstances. As we know, with the passing of the years, those tragic circumstances mean that such sufferers are becoming fewer and fewer in number, and they deserve justice following a 30-year campaign, which has yet to achieve a full acknowledgement "let alone an apology" from the Government for what happened.

Today's debate focuses on the haemophiliacs who were infected with hepatitis C—indeed, all but a tiny number of haemophiliacs receiving those blood products were infected with the virus. However, few, if any, haemophiliacs escaped with a single infection; most were exposed multiple times to multiple genotypes of hepatitis viruses, along with many other types of pathogens—hepatitis A, G, D and B for example. Many are super-infected.

It has been proved that infection with both HIV and hepatitis C exacerbates the progression of each virus. It is time now to look at the wider pictures. Haemophiliacs, many of whom have been infected by multiple viruses, desperately need additional support and proper needs assessments. As a community, they were, over time, knowingly exposed to such viruses, despite the growing warnings.

When we look back at what happened, it is worth remembering that the first warnings were given to the Department of Health in 1958 and yet, as late as 1984, we were still importing blood from America that we knew had been collected in American prisons. Even another five years after that, we were still importing blood supplies about which we knew very little. It is incredible that all these years later, in 2013, we are still having debates in Westminster Hall to try to bring about justice for this group of patients who were scandalously let down by our national health service.

The right hon. Member for Wythenshawe and Sale East made a good point in saying that there has been clear resistance for a long time to having a full-blown public inquiry. He also made good points about the opportunity to go about having one in a slightly different way, with an inquiry of some sort being given full access to all the relevant facts. Such an inquiry would stand a very good chance of getting to the truth of why

the warnings were ignored for all this time.

Grahame M. Morris

The hon. Gentleman is making some very important points, many of which I agree with. However, I seek his views on the privatisation of Plasma Resources UK, the UK's plasma laboratory service. One of the reasons why that was acquired by the last Government was to ensure safe supplies of, among other things, factor 8. Does he think that there is a risk involved in that privatisation, particularly in light of the evidence of what has happenedâ€"tragicallyâ€"to haemophiliacs?

Sir Nick Harvey

The hon. Gentleman makes an interesting point, and there will be anxiety on that front in many quarters. We have to hope desperately that what he is suggesting does not come to pass, because we are going to have to learn the lessons of the past. It is essential that we have proper controls over this sector for the future.

A number of hon. Members have referred to the means by which support is given to the sufferers and their families, and some good points have been made about the two-stage process effectively being a two-tier system. There were also some very sensible suggestions about Atos and the all-work test, because the fact of the matter is that the current system of financial support is patchy and insufficient. The Government need to revisit the issue urgently.

The challenge is partly for the new Health Minister, my hon. Friend the Member for Battersea (Jane Ellison), whom I welcome to her post, but it is also a matter for the Department for Work and Pensions. It must recognise the unique circumstances of this community as a whole and come up with a comprehensive settlement once and for all, so that the victims, the widows and the families affected by the tragedy can get on with the rest of their lives.

I agree very much with those who have paid tribute to the current Prime Minister for having been willing to go into events of the past. He has not always been universally praised for doing so, but he has gone and tangled with some tricky issues from the past. This is another such case and he would be well advised to do the same with it. We have to learn lessons from these tragic events, put things right now and ensure that nothing similar can happen again.

Jim Dobbin (in the Chair)

We have two speakers left and approximately 15 minutes for them both.

10:22:00

Mr Andy Slaughter (Hammersmith) (Lab)

Thank you, Mr Dobbin, for calling me to speak. It is a pleasure to be here in Westminster Hall under your chairmanship.

I, too, thank my right hon. Friend the Member for Wythenshawe and Sale East (Paul Goggins) for securing this debate and for his speech. I welcome the Minister, the hon. Member for Battersea (Jane Ellison), to her post. This is the second Westminster Hall debate in two weeks that I have taken part in and she has responded to, so she has a very full in-tray. Nevertheless, I urge her to study her brief on this issue and, as my hon. Friend the Member for Kingston upon Hull North (Diana Johnson) said, to meet the victims of the contaminated blood scandal and their MPs.

Most importantly, the Minister should come up with a proposal for resolving the remaining injustices on this issue. I am sure that she will; she has a reputation for being thoughtful and open-minded on such subjects, but she will have heard from right hon. and hon. Members today that this problem becomes more pressing with every year that passes.



I am afraid that, as my hon. Friend the Member for Kingston upon Hull North said, the cause was somewhat set back by the meeting that the previous Minister, the hon. Member for Broxtowe (Anna Soubry), had with the all-party group on haemophilia and contaminated blood earlier this year. It is no exaggeration to say that it is the worst meeting I can remember in eight years of going to such meetings. The previous Minister was completely unprepared in her brief; she shared the all-party group's concerns but had no solutions whatever to address them. That meeting was attended by 20 MPs and peers, with 20 others giving their apologies. The number of Members who take part in the frequent debates on this issue shows the level of concern among all parties about it.

This is a great injustice, which successive Governments have failed to address; in so far as they have attempted to address it, they have done so in a miserly and bureaucratic way. An inquiry has been refused, and responsibility has been refused, by Government, and those things are to be deplored.

In the very few minutes that I have to speak, I wish to introduce one additional topic. My right hon. Friend the Member for Wythenshawe and Sale East has rightly framed this debate in terms of contaminated blood and hepatitis C; understandably, the good briefing from the Haemophilia Society has done the same. However, the briefing also refers to co-infection with HIV.

When the Minister looks at these issues, I urge her not to forget those who have been infected, or co-infected, with HIV as a consequence of contaminated blood products. Of the 1,252 people who have been infected with HIV in this way, 932 have died so far. Among the 322 of those people who are still living, one of them is my constituent, Andrew March, who was contaminated at the age of nine. He is now 39, so his entire life has effectively been ruined. He has been a staunch campaigner. He was the applicant in the judicial review proceedings on this matter, and yet after 30 years he is still waiting for any proper redress.

I feel strongly that this issue is the responsibility of Government, and the hon. Member for North Devon (Sir Nick Harvey) was also clear on that. To some extent, the admission of liability is not the central question. The previous Minister wrongly said that the reason why proper payments were made in the Republic of Ireland was that there was an admission of liability. In fact, payments were being made there before the admission was made, as the hon. Member for Foyle (Mark Durkan) pointed out very clearly, having a clear knowledge of what happened; the hon. Gentleman is not here today, but he has done a lot of work on this issue.

We do not need to get tied up in those matters of liability, but personally I would like an admission of responsibility from the Government, because, for some of the reasons that have already been given, much more could have been done. In the 1970s and 1980s, there was a delay because of a failure to see what medical knowledge was showing about contamination. Even when that contamination was known, there was a failure to treat products so that they were no longer harmful.

My final point is about funding. Reference has already been made to the Skipton Fund in relation to hepatitis C, but there are similar problems with the Macfarlane Trust. I have been told that it is effectively falling apart; that the review of its probity, of its success, has been ignored; that there is very poor communication between it and sufferers; and that it is underfunded.

The result of all that is that people die. People die because they are not getting sufficient treatment or sufficient medication that they need to deal with their conditions. HIV is a treatable condition, but for those who have serious health problems it can still be fatal and that issue is not being addressed. In the short term, I ask the Minister to look at both the lump sum and ongoing support payments, but in the longer term what we need is a full and final settlement.

I suspect that many Ministers, particularly junior Ministers, wonder how much difference they have made on a lot of issues when they finally leave their posts. However, I also suspect that this is one discrete area, with a defined number of victims, where the Minister could make a difference if she chooses to put her mind to

it, in a way that some of her predecessors have not.

Jessica Morden (Newport East) (Lab)

A Welsh member of the all-party group on haemophilia and contaminated blood recently told me that every meeting and correspondence that it has with the Government ends with the words, "The Minister will look into this." Does my hon. Friend agree that a promise really to get to grips with this issue now would be incredibly important, not least for Colin—aged seven, from Newport—who died in my constituency from having contaminated blood? We must also remember the very young victims whom we are campaigning for.

Mr Slaughter

I am grateful to my hon. Friend. I know that those views are shared by many Members on both sides of the House.

We are probably not looking for answers today, although we will listen to what the Minister has to say. She has heard clearly that we can do more than just look into the issue: we can achieve results for the remaining victims of these terrible diseases and their families.

22:30:00

Nadhim Zahawi (Stratford-on-Avon) (Con)

I am grateful for this opportunity, and I congratulate the right hon. Member for Wythenshawe and Sale East (Paul Goggins) on securing this important debate. I know that many colleagues feel passionately about the issue. Indeed, one can feel little else when one realises what a long and painful shadow has been cast on the haemophiliac community. They are people who put their faith in a system that has let them down.

I welcome the points raised by other right hon. and hon. Members on the anomalies in financial support for those who contracted hepatitis C. Indeed, those issues have affected one of my own constituents, Mr [GRO-A], who was infected with hepatitis C in the 1980s and has since been diagnosed with polyarthrititis and, most recently, with liver cancer. He has raised with me on a number of occasions the lack of additional support for those with tertiary conditions such as polyarthrititis, as well as his difficulty in obtaining disability benefits, for which previous assessments have been based on his mobility rather than his ability to care for himself and to undertake everyday tasks. Although polyarthrititis affects only some 4% of chronic hepatitis C sufferers, it has had a huge impact on Mr [GRO-A]'s quality of life.

There is another group that warrants significant attention, however: those who contracted HIV through their NHS treatment. When we talk about financial support mechanisms, we should learn from their experience of the Macfarlane Trust, which sadly, is not a tale of best practice. One person said that the trust

"neither cares nor understands what we have been, or are, going through".

Another said that the trust is:

"No longer fit for purpose".

A third person said that the trust is:

"An embarrassment to the government that funds it".

Those are just a selection of the damning descriptions of the Macfarlane Trust that I have received from both beneficiaries and, significantly, trustees. I know that Health Ministers have tried hard to regain the trust of the haemophilia community, but the sad fact is that their efforts are constantly undermined by the failings of the Macfarlane

Trust.

We cannot turn the clock back and undo the damage done, nor can we pretend that we can wholly make up for the years of distress. However, we can, and must, ensure that the support provided by the Government is not administered in a way that serves as a further source of anger, upset and frustration. Yet I hear time and time again that that is the daily frustrating experience of many beneficiaries. The experience is that policies are created ad hoc with little continuity or clarity, that intrusive and personal details are demanded in response to the simplest of requests and that the attitude towards beneficiaries is one of arrogance. Beneficiaries feel at best confused, and at worst bullied, by the very organisation created to support them.

In preparing for this debate, I have spoken to two previous trustees, who both suggested that the management of the trust was completely out of tune with the needs of beneficiaries. They described an organisation that was completely unwilling to make the case for further funding from the Department of Health and that dismissed complaints without due care and attention. Although I recognise that the trust is independent of the Department, the Minister must recognise the harm that is being done and, in turn, how that reflects on her Government.

I know many of those concerns were raised with the Minister's predecessor, my hon. Friend the Member for Broxtowe (Anna Soubry), during the recent AGM of the all-party group on haemophilia and contaminated blood, and I therefore hope that the Minister will continue with the internal review that I understand was subsequently initiated, and that she will agree to meet with representatives from across the community. The community do not want to be perceived as victims forced to go "cap in hand" to beg for support.

Clare Walton, another of my constituents, says:

"I want to be empowered, and have autonomy over my own life, rather than continue with this victim culture through charity."

The sobering reality is that the Government cannot afford to wait another 20 years. The people who need support are dying in ever increasing numbers.

As my hon. Friend the Member for North East Bedfordshire (Alistair Burt) rightly commented, the Prime Minister has an outstanding record of seeking to address historical wrongs. Personally, I cannot think of a better time to address

"the worst treatment disaster in the history of the NHS."

Jim Dobbin (in the Chair)

I thank all hon. Members who have taken part for their time discipline in this extremely important debate.

10:35:00

Andrew Gwynne (Denton and Reddish) (Lab)

As always, it is a pleasure to serve under your chairmanship, Mr Dobbin. I apologise on behalf of my hon. Friend the Member for Copeland (Mr Reed), who was scheduled to respond for the Opposition. Sadly, St Jude's storm meant that he was stuck in the wilds of Cumbria yesterday and was unable to travel down in time for this morning's debate.

I echo the thanks given to my right hon. Friend the Member for Wythenshawe and Sale East (Paul Goggins) for securing this debate on an extremely sobering and important issue that has affected many people across the country. I also welcome the new public health Minister to her post, and I wish her the best of luck.

This has been a powerful debate, with many moving contributions from Members on both sides of the House. I thank right hon. and hon. Members for contributing, including my right hon. Friend the Member for Wythenshawe and Sale East, my hon. Friends the Members for Kingston upon Hull North (Diana Johnson) and for Hammersmith (Mr Slaughter), and the hon. Members for Strangford (Jim Shannon), for North East Bedfordshire (Alistair Burt), for North Devon (Sir Nick Harvey) and for Stratford-on-Avon (Nadhim Zahawi).

We must remember that 4,500 patients contracted HIV or hepatitis C due to one of the gravest failures in modern medicine. That failure hit innocent and trusting people, and, to date, it has claimed thousands of lives. Members from both sides of the House will be well aware of how the rowdier moments in the House of Commons are perceived by our constituents, but I believe that debates such as this, conducted with great dignity while addressing serious failures and harrowing accounts, are a credit to the institution of Parliament, and I look forward to working with the Minister to help reach a speedy and satisfactory outcome for those who are campaigning for support to maintain a good quality of life.

The failures in our health system in the 1970s and 1980s, and the struggle for help and support fought by those affected, are a stark reminder of our responsibilities in this place. As we have heard today, progress has been painfully slow—that point was eloquently and powerfully put by the hon. Member for North East Bedfordshire. The previous Government and the devolved Administrations established the Skipton Fund in 2004 to make ex gratia payments to those who were infected.

In May 2009, Lord Archer published a report on NHS-supplied contaminated blood and blood products. We implemented many of his recommendations, including giving the Haemophilia Society £100,000 for haemophilia doctors and committing to phasing out prescription charges for patients with long-term conditions.

In April 2010, the then public health Minister, Gillian Merron, decided to bring forward a review of the Skipton Fund—we had previously committed to reviewing the fund in 2014. Announcing that decision, she said:

“We have listened carefully to the views of those infected, their families, carers and many in this House, who have told us that our intended review date of 2014 will be too late for many of those affected.” [Official Report, 6 April 2010; Vol. 508, c. 133-134WS.]

I welcome this Government’s work in continuing to build on the foundations laid by the previous Government. The issue must transcend party politics. Our focus from now on must be on what we can do to support those who bear financial burdens as a result of contracting hepatitis C or HIV.

I hope that the Minister is able to give us a comprehensive account of what the Government are doing to build on the actions set out by the Leader of the House when he was Secretary of State for Health in his statement to the House on 10 January 2011. He announced changes to the financial support schemes for those infected with HIV and hepatitis C, including the introduction of an annual payment of £12,800 for those with the most serious hepatitis C-related disease as a result of NHS blood transfusions and blood products, in line with payments received by people infected with HIV. Those groups need Government support more than ever, and I want the Minister to give assurances that work on this issue will not be undermined by budget reductions.

I cannot even begin to imagine the pain and suffering inflicted on the victims who received infected blood. To those who relied on receiving blood regularly as part of their treatment for haemophilia, only to have a life-changing diagnosis thrust on them; to those still facing daily challenges; and to the dependents of those who are, sadly, no longer with us, we owe help, support and justice.

I pay tribute to the work done by the many campaigners and organisations across the country, which is a credit to the tireless efforts of those affected and their families. Their efforts could have been no better espoused than by my right hon.



Friend, who set out the experiences of his constituents. It is right that such people are exempt from the Atos processes, and my right hon. Friend's points about the financial burdens that such things put on families were extremely timely. Changes to qualifying criteria for a range of illness-related benefits will unnerve those who depend on such income to make ends meet. I am sure that the Minister will welcome this opportunity categorically to state that the Government will protect payments to those who have been affected. Leaving aside the health issues caused by the transmission of infections, the stress brought on by worrying about bills and security can have an extremely damaging impact on the lives of those concerned.

On top of dealing with financial concerns, we must provide a health care system that makes it as easy as possible for people with hepatitis C to use the services they need to maintain a good quality of life. I therefore hope that the Minister can give us an indication of the reforms that are being made to support patients.

My right hon. Friend's proposal to unite stage 1 and stage 2 under one fund warrants serious consideration, and I would welcome a pledge from the Minister seriously to look at it and to try to bring it about. My right hon. Friend was also right when he said that the Government must take any action in conjunction with those who have been affected.

As I said, this is not a debate for political point scoring, and I assure the Minister that the Opposition want to see swift action to ensure a good outcome for those affected—something eloquently pledged by my right hon. Friend the Member for Leigh (Andy Burnham), the shadow Secretary of State for Health, in an intervention earlier. We will therefore be happy to work with the Government to introduce proposals finally to achieve a good and proper conclusion for those affected and their families and, I hope, to draw a line under one of the darkest failings seen in our country.

10:43:00

The Parliamentary Under-Secretary of State for Health (Jane Ellison)

It is a pleasure to serve under your chairmanship, Mr Dobbin. I thank all hon. Members who have contributed. This is not the first such debate I have sat through; as a member of the Backbench Business Committee, I helped to allocate the Back-Bench debate in 2010. I sat through that whole debate, so I came to this post at least familiar with the strength of feeling on this issue and with the way in which so many hon. Members have worked so hard over many years to represent their affected constituents.

Inevitably, at the beginning of week four of my time in office, I must, I fear, disappoint those hoping for new policy announcements. The debate has perhaps been more useful for me, listening to Members' contributions, than it will be for those listening to me. It has been incredibly helpful to hear the many comments that have been made, and I will try to answer as many as I can. If I do not have the knowledge or time to answer any points, I undertake to write to hon. Members about them. Let me also say straight away that I am more than happy to have the meetings that have been asked for. I have some thoughts about how we can get the most out of them and make sure they give us a platform on which to move forward.

I thank all those who have contributed to the debate. I congratulate the right hon. Member for Wythenshawe and Sale East (Paul Goggins) on securing it on behalf of those with haemophilia who were, sadly, infected with hepatitis C as a result of treatment with blood products before 1985. Many Members have talked about the impact on constituents, and that has come home very forcefully to me.

Members have given me much to reflect on, but I would like to take some time to lay out the current position. Everyone who has spoken has said they would prefer us to be somewhere different, but it is relevant to lay out the practical support that has been offered to date and where successive Governments have got to. Indeed, the presence of a former Secretary of State at the beginning of the debate rather underlined the fact that successive Governments have struggled to achieve a final resolution. I very much welcome the cross-party tone of the debate and the shadow Minister's commitment to work with the Government.

The Government are fully committed to supporting affected haemophilia patients, by ensuring that haemophilia and hepatology services in the NHS are as good as possible and by providing direct financial assistance. There is the prospect of some good new treatments for hepatitis C, with fewer side effects than the current treatment and less of an impact on day-to-day life. We all welcome that, but I recognise that although these new therapies may treat the infection, they may not alleviate all the associated health effects. For many of those affected by hepatitis C, there is a continuing need for support.

In January 2011, my right hon. Friend the Member for South Cambridgeshire (Mr Lansley), then the Secretary of State for Health, informed the House that we would provide additional support for those affected. It is important to remember that that support was available to not just haemophilia patients, but any patient infected with HIV or hepatitis C by an NHS-supplied blood transfusion before 1991.

Although many who have spoken this morning are seeking a longer-term resolution, let me quickly go through the additional practical support that the Government have put in place. We linked the annual payment for HIV awarded by the previous Government to inflation, so it does not lessen in value. We introduced a similar payment for those most seriously affected by hepatitis C, and we increased the value of the lump sum for that group to £50,000. I very much hear the concerns some Members expressed about the divisiveness of separating different groups, but the lump sum for that group was nevertheless increased substantially.

A discretionary payment mechanism was also introduced to meet specific financial needs for all those infected with, or affected by, hepatitis C. None of those affected now have to pay for their prescriptions. In addition, £300,000 has been made available over a three-year period to provide counselling services to those affected by hepatitis C. All those payments are tax-free and are disregarded for the purposes of benefits and determining eligibility for social care services.

To pick up the point about the exemption regarding employment and support allowance, one of my predecessors made representations in that regard. The issue is not in my remit, and the decision is obviously for the Department for Work and Pensions, but I certainly undertake to raise the issue as a result of the debate and to revisit it with the appropriate DWP Minister.

A combination of fixed and discretionary payments was previously decided on as the best way of ensuring greater financial certainty for people facing the most severe consequences from infection. The idea was that it would retain a degree of flexibility so that assistance could be tailored to an individual's personal situation, and the debate has clearly shown how different the situations of hon. Members' constituents are.

The set-up put in place could also complement the other support people might receive, such as through the benefits system. The flexibility that gave was thought to be important, because an individual's needs vary significantly. However, I know there is concern among haemophilia patients and others infected with hepatitis C that there is insufficient support—this has been the focus of much of the comment today—for those who have developed chronic infection, particularly Skipton Fund stage 1 beneficiaries, on whose behalf many Members have eloquently spoken.

The scientific and clinical advice that the Department received during the review did not support the case for making regular annual payments to all those infected with hepatitis C. I am advised that some people with chronic hepatitis C infection clear the virus, and that those numbers could increase with the new therapies that are emerging. Decisions on financial support have been informed by the evidence, where that is available.

The spectrum of possible consequences of hepatitis C infection appears to be wide-ranging, and, in many cases, causal association has not been established. That has been a problem in the past. Ministers were grateful for the advice of experts on that area—a complex one, obviously—ahead of the 2010 review. Following the review, the

then Minister with responsibility for public health, my hon. Friend the Member for Guildford (Anne Milton), promised that new evidence would be assessed regularly. That challenge was put to me several times in the debate. Those assessments will help with future decisions whether to make changes to the payments system.

The advisory group on hepatitis recently completed its first assessment of the clinical and scientific evidence published since the 2010 review, and the Department has sought further detail from the group on some of the information in the report. Some people affected by hepatitis C dispute the expert interpretation of the evidence, so Department of Health officials have commissioned a systematic review of the scientific and clinical evidence on the natural history of hepatitis C. That will report in autumn 2014. I shall raise with officials the question whether that could be brought forward. An earlier report could be useful in the light of other events.

We hope that, in addition to providing a definitive analysis of the available evidence, the systematic review will be of value for service planning in the NHS. Several hon. Members have referred to other parts of the NHS and the provision made for continuing care, so I think that the exercise has additional value. The hon. Member for Kingston upon Hull North (Diana Johnson) made the case, and although I cannot respond to her detailed points and questions about some distinctions that are made, we are aware of the dispute. I undertake to write to her if I can respond in more detail.

Several trusts have been mentioned this morning, but I understand that beneficiaries of the Caxton Foundation have not always found it responsive to their needs. This morning, hon. Members have expressed concerns about how it has operated since it was established in 2011. I have seen recent correspondence between campaigners and Caxton Foundation trustees, so I am aware of some of the unhappiness.

I want to give reassurance on one point: the foundation has £2 million for payments in England and has not yet spent all the money available to it. If it needs more money, it can make a business case to the Department. I understand that it will be doing so this year, and we shall consider that on its merits. It has been working hard to improve its services in the past year and has already established some processes to: reduce the time between application for and payment of straightforward grants, an issue mentioned by several hon. Members in the debate; make payments in the form preferred by the beneficiary; and continue to review where it can improve further.

The hon. Member for Kingston upon Hull North made points about published criteria for the application process, means-testing and specialist doctors. Those are all detailed points that I shall consider, and on which I shall respond to her, but I shall need to make contact with the foundation, because all decisions about payments are made by the trustees. I do not have the power to direct them on how to make decisions, but after the debate I intend to write to remind them that the trust deed enables them to meet any charitable need and not just those that arise directly from an individual's hepatitis C infection. If hon. Members have other points that they want to raise with me, I shall be happy to put them to the foundation. Clearly, some of those that have been raised this morning are matters for concern.

Several right hon. and hon. Members have talked about public inquiries, or a process of truth and reconciliation. The right hon. Member for Wythenshawe and Sale East made interesting points about different approaches in recent years. I shall reflect carefully on what he said, which I think other right hon. and hon. Members supported, about considering different approaches.

The Department of Health has put relevant facts for the period in question "1970 to 1985" in the public domain, on its website; however, colleagues have called for more material to be put in the public domain, and I shall reflect on that, as well as on what has been said this morning about the different models of truth and reconciliation processes. It was interesting, and it is something for me to reflect on.

Alistair Burt

I thank the Minister for what she has said about her openness with respect to the inquiry. I recognise that she is new to her post, but if there is one subject that the

Department knows all about, it is the one we are debating. It has all the information it needs.

I do not expect the Prime Minister to come to a definitive decision at the meeting in a couple of weeks about what he or the Department can do, but I hope that the Department will give a briefing of the right tone, saying that there is an opportunity to settle the matter. Somewhere among the optionsâ€"either the first or the lastâ€"is the one that settles things. It has existed for some time. I ask my hon. Friend to do all she can, using the same spirit as is in her response on opening things up through an inquiry, to point the Prime Minister in that direction, so that as he deliberates on the question and she finds her feet in dealing with it, we can, as the debate has urged, move towards finding a way to close the matter.

Jane Ellison

My hon. Friend makes fair points. I spent much of the past three years chasing him in his previous role to put right a continuing historical wrong, and he is right to push me in the same vein. I take his remarks, as I have always taken his advice and thoughts, extremely seriously, and will reflect on them.

I want quickly to mention the Penrose inquiry, of which I am very aware. As the hon. Member for Kingston upon Hull North said, it will report in the spring. Right hon. and hon. Members may be interested to know that the Department of Health has provided all reasonable assistance to Lord Penrose, explaining what documents are held in the Department.

Mr Tom Clarke

Will the Minister give way?

Jane Ellison

May I continue, as I fear I will not get through the remaining points? I will be happy to speak to the right hon. Gentleman straight after the debate.

We have made available to Lord Penrose any additional documents that he has felt are necessary to his inquiry. While it is continuing, I shall not comment on the inquiry or evidence given to it, but I shall consider whether the Department will make a response. Given that Lord Penrose is considering pre-devolution matters, it is hard to imagine that there will not be implications to which I and the Department shall need to respond. We do not know the exact shape of things, but the inquiry is on my radar, and we shall be considering it.

The hon. Member for Easington (Grahame M. Morris) made a point about specialist hepatitis C nurses. That is the responsibility of NHS England, and I undertake to write to that body to draw its attention to his comments.

I think that I have now covered most of the specific points that I can answer today; unfortunately, I cannot respond to some of the detailed points. There was a challenge about the number of Skipton Fund stage 1 beneficiaries; there are difficulties in identifying the numbers, but we will examine that issue and see whether we can respond in more detail to the challenge given by the hon. Member for Kingston upon Hull North.

Inevitably the debate has been, for me, an invaluable opportunity more to hear some of the arguments than to give specific answers on the important points that colleagues have raised so well on their constituentsâ€™ behalf. I am happy to have the meetings that have been suggested.

Nadhim Zahawi

Will the Minister give way on that point?

Jane Ellison



If my hon. Friend will forgive me, I need to conclude.

I have heard the big challenge that I have been set this morning. It is one that many of my distinguished predecessors have been set, and I do not underestimate its nature or scale. There is, and has been for a long time, great unhappiness about this topic; many people have wrestled with it. I assure right hon. and hon. Members that I will do my best to rise to the challenge.